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ENDLESS NIGHT, ENDLESS MOURNING: LIVING WITH ALZHEIMER'S

HEARING

BEFORE THE

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UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

FIRST SESSION

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ENDLESS NIGHT, ENDLESS MOURNING: LIVING WITH ALZHEIMER'S

MONDAY, SEPTEMBER 12, 1983

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
New York, N.Y.

The committee met, pursuant to notice, at 10:30 a.m., at the Jewish Home and Hospital for Aged, New York, N.Y., Hon. John Heinz, chairman, presiding.

Present: Senators Heinz and Pressler.

Also present: Tricia Neuman, professional staff member; Isabelle Claxton, communications director; Claire Smrekar, legislative correspondent; and Angela Thimis, hearing clerk.

OPENING STATEMENT BY SENATOR JOHN HEINZ, CHAIRMAN

Chairman HEINZ. Good morning, ladies and gentlemen. The hearing of the Senate Special Committee on Aging will come to order. We are meeting here today to hear testimony on one of the most frightening illnesses to strike the elderly, Alzheimer's disease.

This insidious form of senile dementia plagues between 1 and 3 million persons over age 65. Because we know neither cause nor cure for this horrid condition, the onset of Alzheimer's brings infinite pain to patients and family caregivers. For those afflicted, living with Alzheimer's is a lonely irreversible path into an endless night.

For the family members, this irreversible journey means a struggle to provide continuous emotional support and physical care, often at great expense. With no cure in sight, their years of providing care are spent in endless mourning. While Alzheimer's disease and related research activities have been the subject of recent congressional hearings, today's hearing will focus on the issue of care.

Earlier this year, Senator Larry Pressler, my esteemed colleague here with us today, suggested that the Aging Committee hold a hearing on Alzheimer's disease. Recently, he chaired a hearing in his home State, South Dakota, on this very topic. Senator Pressler has been a leader in the Senate, working to focus national attention on this dreadful disease. Senator, I commend you for your dedicated efforts on this most important topic.

I agreed with Senator Pressler that this was an important subject for committee attention for several reasons. First, this hearing provides a forum for our committee to learn more from family members and professional caregivers about what is being done, and what more we can do for them, as well as for the patients.

Second, by convening in New York City, we have the opportunity to hear from active city leaders who are dedicated to improving life for older Americans, evident in Mayor Koch's upcoming conference on Alzheimer's disease.

I might also add that it is particularly appropriate that we are meeting here at the Jewish Home and Hospital for Aged, where the staff prides itself in offering the best possible care for its 250 patients with Alzheimer's.

Finally, with this hearing, I hope to generate support for the long-term care legislative package I introduced earlier this year.

As chairman of the Senate Aging Committee, I see this hearing as an important opportunity to consider not just issues related to Alzheimer's disease, but also the more general issues that loom over the American long-term care delivery system. We all are increasingly aware of the need for long-term care reform. More people are living longer, requiring more care, at home, in the community, and in nursing homes. Given current demographic projections, the demand for services is certain to mushroom.

Currently, families are providing a substantial portion of care for the chronically ill. For example, at least half of those with Alzheimer's disease are cared for at home. We recognize the great financial and emotional price tag of providing around-the-clock care in the home. It is time now to assist these caretakers by easing the financial burden and by making available more home and community-based services.

During the past several months, I have been working with several members of the Senate Finance Committee to put together a package of bills to help provide additional long-term care services. Each of these bills, the Home Health Tax Credit Act, the Health Care Coordination Act, and the Independent Community Care Act, would, if enacted, make it substantially easier to care for older family members, including those with Alzheimer's disease, in the home.

Don't let me mislead anybody that home care is the only appropriate method of dealing with problems such as Alzheimer's. It is not. There is a substantial portion of the population, that must have access to institutional care, such as the excellent kind of care given here.

It is my hope that the committee and Congress will take further action in the long-term care area. We are here explicitly today to learn what more we can do and how greatly we need to do it.

Let me just say, before I yield to Senator Pressler for his introductory remarks, how pleased I am that Senator D'Amato is here. Senator D'Amato, although not a member of the Aging Committee, is entitled and invited to sit with us this morning. When Senator D'Amato heard we were having this hearing, he came to me and said he really cared about the problem. It was a major problem for the people of his State.

He has thoughts he wants to share with the committee and wants to testify before the committee and participate in the hearing. I want to commend your Senator, Senator D'Amato, on his initiative.

The Senate, if you believe what the newspapers say, is either in session this morning or has not yet returned from vacation. In any event, Senator D'Amato is here, because he cares about this problem and because he cares about his constituents.

Al, I commend you.

STATEMENT BY SENATOR LARRY PRESSLER

Senator **Pressler**. Mr. Chairman, I shall be very brief, so we can hear the witnesses and hear Senator D'Amato. I want to begin by commending Senator Heinz and his staff for the outstanding work they have done in organizing this hearing. His staff, particularly, should be commended because they have been most cooperative, as has Senator D'Amato's staff. Often, the staff people do the work in organizing these things and do not get the recognition they deserve.

I had not really heard of Alzheimer's disease before about 5 years ago. I had a personal reason for learning about the disease—my father contracted it. Since that time, I have become very well informed about it. This tragic disease is costing the country in the neighborhood of $26 million a year, in terms of nursing home costs, home health care, and lots of other costs, such as loss of productivity. I believe that it is time we all become well informed about it.

The point is, that if we could find a cure or a treatment for this disease, we could save a lot of money, besides preventing the tragic human losses involved.

I want to commend the media, for their assistance in this effort. In the last 2 years, Alzheimer's disease has become a subject in the forefront. We are starting to realize that a large portion of our nursing home admissions are a result of Alzheimer's disease. We are waking up to the fact that this is a big factor, not only for the elderly population, but in terms of what we previously would have defined as senility.

We also are struggling to redefine some of the medicare regulations under which degenerative diseases are not covered. Increased funding for research also is needed. I sponsored an amendment in the last Congress to increase the funding for the National Institute on Aging by earmarking funding for Alzheimer's research. I believe this is most important.

In the very near future, we will be going to Senator D'Amato, who is on the Appropriations Committee, to seek more funding for research. This research will save money in the long run, aside from the human losses that could be prevented.

Let me say that I know that we are going to hear from many important witnesses today, including representatives on the Alzheimer's support group. In the last 3 to 5 years, Alzheimer's support groups have sprung up across the country. Recently, I held a hearing in Sioux Falls, S. Dak. The Alzheimer's Disease and Related Disorders Association has a very large support group for the spouses and loved ones of those suffering from Alzheimer's disease in that city. They meet and discuss how to cope with the diseases, especially in its early stages, where the patients are cared for at home. The association has increased awareness about this disease.

It is within the last 3 years that we have seen several TV specials and several articles written about Alzheimer's disease. This tragic ailment has become better known, thanks to the efforts of the media. We have lots of work to do. If we could find a cure or treatment for this disease, we could save a lot of human anguish, and save a lot of money, at a time when we have a $200-billion-budget deficit.

I have joined Senator Heinz in sponsoring legislation, like S. 1301, which would allow tax credits for expenses incurred in the care of elderly family members.

We must get the National Institute on Aging to focus more of its attention on this disease. That is where Senator D'Amato will be a key, as a member of the Senate Appropriations Committee, as will Senator Heinz of the Finance Committee.

Today, we are at a nursing home and hospital that has between 600 and 1,000 beds, depending on how you define them. In South Dakota, where I chaired a hearing on this issue last month, nursing homes averaged around 40 beds. While each State has a different set of problems, Alzheimer's disease is a threat to us all.

I have had discussions with my State's nursing home directors about the new prospective payment regulations. We sometimes take a different point of view on the way some of these programs are structured. That is what these hearings are all about.

We will take back to Washington what I learned in the rural areas, as we will take back what we learn here today. Then the Congress will have to mesh it together, and that is a difficult job.

We are here today to learn things we can use legislatively in dealing with the tragedy of Alzheimer's disease.

I wrote an article on Alzheimer's disease for People magazine, July 12, 1982. It is two pages long. I would like to insert that article into the record.

Chairman HEINZ. Without objection, so ordered.

[The article referred to follows:]

BY LARRY PRESSLER

For many people, life's later years are a time for long-neglected interests and happy recollection, but to an unfortunate minority, they bring something quite different. Senile dementia, a complex of brain disorders whose causes are often unknown, is found in as many as 15 percent of those who live past the age of 65, frequently robbing them of memory, intellect and independence. Like most diseases, senility strikes without discrimination. It affects former movie stars such as Rita Hayworth, 63, now the helpless victim of a neurological form of the ailment known as Alzheimer's disease, as readily as Antone Pressler, a rugged farmer from the prairies of South Dakota. Pressler, 66, is the father of Larry Pressler, 40, a former Rhodes scholar, Harvard Law School graduate and, since 1978, Republican Senator from South Dakota. For the past seven years the son has witnessed his father's steady mental decline and observed the difficulties his worsening senility has posed for those around him. In a conversation with PEOPLE correspondent Clare Crawford-Mason, Larry Pressler told how his family gradually came to grips with an illness that now afflicts an estimated 1.5 million Americans.

COPING

A FATHER'S SENILITY BECOMES A LOSING BATTLE FOR A U.S. SENATOR AND HIS FAMILY

My father was a struggling farmer most of his life. He grew up in rural South Dakota, married a local girl and raised five children on a 140-acre farm. He took pride in being an outdoor, working man who was in great shape. He never complained about any sickness, he didn't have annual physicals, and I don't think he was ever in a hospital in his life. He didn't drink, except for a beer once in a while, and he never even took aspirin.

He and my mother lived their whole lives within a 12-mile radius of their farm outside Humboldt. On Sundays they'd visit relatives or maybe go to a local ball game, and that would be their recreation. During the week he would get up about 6:30 a.m. and spend an hour and a half feeding the cattle and the hogs, then take the tractor and haul hay or plow or cultivate his corn. He was 59 years old, and you'd never have guessed seven years ago that his mind was slipping a little bit.

Some of it was just taken as forgetfulness. Nobody paid much attention when Dad would take a load of feed to town to have it ground and, instead, sell it. Or he would mow a field of hay and then go out and remow it. He worked alone, and that's probably one reason why people didn't notice anything. His style was always very low-key, and he just did his own thing in his own way. He was the sort of person who, when you asked him a question, would pause for about 30 seconds before he would answer. We didn't notice when the pauses got longer and longer.

Eventually some of the things he did he couldn't explain. He'd forget to water the hogs, or leave a gate open so the livestock would get out. My mother was the type who wouldn't go out of the house very much, but increasingly she had to check on the cattle and the hogs to make sure they weren't running around. A couple of times after he'd forgotten to water the pigs, a few died.

Then over two or three years Dad's behavior got progressively worse. He had periods of lucidity when he could talk about politics or do the farm work very well, and then there were periods when it was just patchy. I was in the House of Representatives then, and I'd talk to my mother by phone from Washington. She kept saying, "He forgets so much," but I thought he just seemed to be aging a little bit. I suggested that she buy some feeder calves that didn't require so much attention, but my mother said, "No, he just can't take care of them." That's when I realized it was serious.

Dad was taken to doctors in Sioux Falls, and they thought it might be some kind of cerebral atrophy. It was diagnosed in one instance as Alzheimer's disease, but doctors really can't be certain without examining some of the brain tissue in an autopsy. During one examination, a doctor asked my father who the President of the United States was, and he couldn't respond. Although he didn't follow politics real closely, he certainly would have known that. I figured that there must be some kind of drug he could take or some

CONTINUED

Dad was 58 and "at the tail end of his good health," says Larry, when the Presslers visited their son in Washington.

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exercises, but they didn't prescribe anything.

I couldn't accept that, so I arranged for a trip to the Mayo Clinic. Dad didn't actively resist and was quite docile, as though he really didn't fully comprehend what was happening. At the Mayo they were never able to define his problem either; they said it could have been a series of strokes, a premature hardening of the arteries in the back of the head, Alzheimer's disease or just aging. There was no record of anything like this in his family; both his father and grandfather had been alert until their 70s. The doctors had neither an explanation nor a cure; they said it's just a process some people go through.

That must have been five years ago. Mother was absolutely determined to keep him at home, so they stayed on the farm for several years more. Once he took a walk in the cornfield, and some of the neighbors had to come and help look for him. Corn will get about eight feet high, and he would lie down in it and take a nap. We had a fence around the garden, though, and when we put a piece of twine over the latch, he couldn't figure out how to open it.

Dad lost his power of speech at some point, and he began mixing his days and nights. There was a visiting nurse who came about once a week to help Mother a little bit and give her advice. That was great because Mother was on the farm all alone with Dad, and she couldn't go to town for shopping and leave him. Eventually he became bedridden and incontinent, and she had to feed him by hand. He could sit and look at TV, but whether he comprehended it or not it was difficult to say.

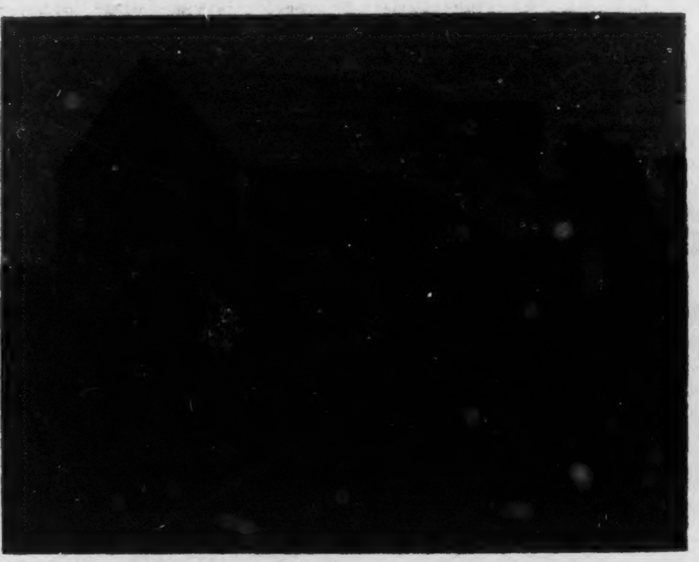
Finally we all thought it was getting to be too much for her. She's the kind of person who just sticks with it, and it was only when she had to have a hysterectomy and go to the hospital for a week that the thing came to a head. She just decided that during the recovery period she wouldn't be able to take care of him and agreed reluctantly that he should go to a nursing home in Canistota, which is seven or eight miles away. None of the family was opposed at that point.

Still, having him in a nursing home has been almost like losing part of my father without really losing him. He doesn't recognize people now, as far as we can tell, and it's always a strange thing to sit down and try to talk to him. He might be aware of a presence, but I don't think he knows I'm there. Mother visits him probably every other day or every third day and has adjusted amazingly well to this difficult situation. She feels badly about it, but she feels the nursing home is doing such a great job and goes over and sits with the ladies who work there. At 64, she's a very hardy individual.

My dad had been getting disability payments from Social Security because he became ill before he was 65. Now his Social Security check goes to the home, plus some additional money from my mother. It's been a great burden for her, but she's taking care of herself. The children contribute some to her support, and fortunately she's been able to rent some of the farmland and collect money from that. There hasn't been a lot of complaining, and maybe that's a trait of Midwestern farmers. They just sort of accept things and do the best they can.

In fact, I don't know how this thing could have been prevented, even if it had been diagnosed earlier. If it's Alzheimer's disease, as doctors now believe, there's no cure for it, and there probably wouldn't have been any difference in the sequence of events. It certainly points up the limits of our power as well as the fragility, the unpredictability of human existence.

It seems very unfair to me, though, to see Dad in this condition. He would have been horrified because he never wanted to be dependent on anybody, and now he's spent the last few years totally dependent on other people. I've often imagined what he'd be like at this point if he were still healthy. He probably would have just kept on farming as his own father did, rather than taking Social Security. He enjoyed moving around and working the farm, and I'm sure he would still be going full speed if he only could. ☐



Pressler comforts his mother during a visit home but worries that "she doesn't like to do things without her husband."

Photographs by Barry Staver

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Senator PRESSLER. I conclude by again thanking you, Mr. Chairman, and to you Senator D'Amato, we will be coming to see you on the Appropriations Committee soon. We are glad to see you here.

I also want to thank the home for hosting us. I understand that the Jewish Home and Hospital for Aged is one of the oldest in the country, and has provided services in one form or another for many years. This goes back to the last century, as I understand it.

So, it is an honor to be here. I am a Senator from South Dakota, far away from New York. I am here to listen to the problems and learn, as I am sure my colleague, Senator D'Amato listens to your problems.

Thank you.

Chairman HEINZ. Lest you feel that Senator Pressler has never even flown over New York, it should be pointed out that as a Rhodes scholar I know he had to get from South Dakota to Cambridge, in England, and he must have been in New York on some previous occasion.

Thank you for your excellent statement.

I commend Senator D'Amato and welcome you. Thank you for being here.

STATEMENT BY SENATOR ALFONSE M. D'AMATO

Senator D'AMATO. Let me thank you, Mr. Chairman, and the Special Committee on Aging for bringing this important hearing on this problem, to New York City. This disease plagues not only New Yorkers, but our seniors throughout the Nation.

I also commend Senator Pressler for his interest and for his thoughtfulness in this area, and for the concern that both you, Mr. Chairman, and Senator Pressler bring on behalf of the families and those who are afflicted with Alzheimer's disease.

I am indeed thankful for the opportunity of being able to testify on this dreaded disease that brings personal and financial tragedy to the suffering and their families.

I realize that more Federal involvement is certainly required, and hopefully we can discuss those possibilities.

I am honored that the Special Committee on Aging has asked me to testify at this important hearing on Alzheimer's disease.

When I was elected to the Senate in 1980, I promised the elderly of New York State that I would further their causes in Congress. After becoming familiar with the devastating effects of Alzheimer's disease, or senile dementia, on both the sufferer and their families, I realized that more Federal involvement was required on research into the causes, treatment, and cure of this dreadful disease.

Alzheimer's disease is a common disorder that destroys certain vital cells of the brain, resulting in senile dementia. Although possible at any age, it is most common with those over 65 years of age. The symptoms of Alzheimer's disease are slow and treacherous. Memory is the first casualty. There is no known cure for Alzheimer's disease. It is irreversible and the deterioration process is unrelenting. Most tragically, it is one of the most ignored diseases in our lifetime.

The scenario for an Alzheimer's disease sufferer is saddening. The slow deterioration of the mental capacity is usually viewed as a normal aging process. This, as we all know now, is simply not true. Alzheimer's disease is a pathological disorder. As the disease progresses, the sufferer becomes dangerously forgetful and increasingly detached. Finally, when an Alzheimer's patient has been institutionalized, he or she may die a near vegetable.

Up to $20 billion annually is spent on Alzheimer's disease. It is believed that close to 25 percent of all nursing home patients suffer from this hopeless disease.

Where there have been some encouraging advances in the study of Alzheimer's disease, we still have a long way to go. Meanwhile, the toll this disease has on the elderly is tragic. Alzheimer's disease affects 5 to 10 percent of those over 65, up to 1 million citizens. It is estimated that 100,000 people die annually from Alzheimer's disease. Since the number of Americans over the age of 65 is increasing, these figures will also increase.

Though there are many theories on the cause of Alzheimer's, there is little now we can do for the sufferer. Many drugs are being tested to improve cognitive functions by the sufferer, but the afflicted, in most cases, die a slow and sad mental death. It is just, therefore, that the Federal Government is taking the initiative with Alzheimer's disease. Research funding is now approximately $22 million.

Mr. Chairman, as you and I and Senator Pressler have discussed both in the Senate and here today, this is simply not enough. We must, on the Federal level, rededicate our efforts by more than just rhetoric.

Therefore, I am pleased to suggest to this committee that I will work with both you and Senator Pressler in doubling the amount of money that the Federal Government now designates to that area of research. I believe that by doubling those funds, we will show a substantial increase in dementia breakthroughs. This will be a prudent investment.

In addition to doubling the amount of money for research of this dreaded disease, I think it would be more beneficial to have a coordinated effort between the various concerned institutes to see to it that this research is done in such a way as to maximize the benefits.

My statement continues on and on. It relives the horrors of many who were asked to come here today. They have seen how this disease strikes not only the victim, but the family and society.

Certainly, there can be no greater area of concern for this committee. It should commit itself to the kind of research capabilities that eventually will bring this disease under control.

I once again would like to commend your leadership, Senator Pressler and Senator Heinz, and I pledge to you both that I will work with you in this session of Congress to give some real meaning and substance to the battle against Alzheimer's disease.

I believe some of the evidence that has linked aluminum concentrations found in the brain, with the question of whether acid rain or certain kinds of diets, and use of certain materials, have aided researchers in finding the elusive cause of this dreaded disease. I am certain our researchers can find the cause and cure if we give them the tools, finances, and firepower to do it.

To that extent, I look forward to not only pushing for more research funding in my capacity as a member of the Appropriations Committee, but also, John, I would be delighted to cosponsor your legislation, S. 1301, that offers aid to Alzheimer's disease sufferers and their families.

Thank you very much.

[The prepared statement of Senator D'Amato follows:]

PREPARED STATEMENT OF SENATOR ALFONSE M. D'AMATO

I am honored that the Special Committee on Aging has asked me to testify at this important hearing on Alzheimer's disease.

When I was elected to the Senate in 1980, I promised the elderly of New York State that I would further their causes in Congress. After becoming familiar with the devastating effects of Alzheimer's disease, or senile dementia, on both the sufferer and their families, I realized that more Federal involvement was required on research into the causes, treatment, and cure of this dreadful disease.

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Where there have been some encouraging advances in the study of Alzheimer's disease, we still have a long way to go. Meanwhile, the toll this disease has on the elderly is tragic. Alzheimer's disease affects 5 to 10 percent of those over 65, up to a million citizens. It is estimated that 100,000 people die annually from Alzheimer's disease. Since the number of Americans over the age of 65 is increasing, these figures will also increase.

Although there are many theories on the cause of Alzheimer's disease, there is little now we can do for the sufferer when he or she contracts this disease. Many drugs are being tested to improve cognitive functioning by the Alzheimer's patient, but the afflicted, in most cases, dies a slow and sad mental death, even though the physical being may last for years longer.

It is just, therefore, that the Federal Government is taking the initiative with Alzheimer's disease. Research funding for senile dementia is now approximately $22 million. This figure should increase to $25 million in fiscal year 1984.

I commend the Secretary of Health and Human Services, Margaret Heckler, for her concern over this disease. She has assembled a task force on Alzheimer's disease to develop a strategy for dealing with this disease. I expect fine results from this task force. Currently, federally funded senile dementia research is conducted by four separate agencies. I hope this task force will recommend a more consolidated Government effort.

I also believe more should be done to help the sufferer and their families cope with Alzheimer's disease. The immediate cause for worry about an afflicted Alzheimer's disease patient is personal safety. As we all know, simple absentmindedness causes many accidents, but senile dementia can be fatal. In the disease's later stages, precautions must be taken to protect the sufferer from his or her own unwitting actions.

The next biggest worry is the high cost of caring for these sufferers, it is estimated that over $17,000 per year is spent on each Alzheimer's disease patient. In the initial stages of the disease, frequent visits to doctors and possible loss of employment could amount to much of the total financial burden. Although this disease mostly affects the elderly, medicare does not cover its expenses. In a recent letter I received, the spouse of an Alzheimer's sufferer was frantic because she had only enough money to last, at most, for another year of paying for nursing home care for her husband. Besides being a monumental emotional burden, Alzheimer's disease also becomes a financial burden.

It would be tough to imagine watching a loved one slowly drift away from you. I am aware of many stories where husbands or wives of Alzheimer's patients are forced to put their spouses into institutions against their will to do so. The afflicted must eventually be cared for like a small child. As this disease progresses, the family often experiences tremendous stress at seeing a family member mentally digress. As one recent magazine article stated, "For the family, it is a haunting sense of loss of the person who is still with them." The family feels guilty because they are able to do so little.

There are, however, many groups around the Nation that assist these families. Discussions in these support groups center around helpful suggestions to make life easier for sufferers and their families. Many groups actually assist the family by providing professional day care in a homelike environment. Services like this help delay the sorrow and expense of institutionalization. It is my wish that these factors also be considered when addressing the problems of Alzheimer's disease.

Obviously, finding the cause and cure for Alzheimer's disease is the most important objective, but as we find out more information regarding this disease, we must also help care for the current sufferers and their families.

Alzheimer's is a tragic and silent disease that must be stopped. In this age when we live longer than ever before, many of our elderly are still experiencing the oblivion of Alzheimer's disease.

Before I join this distinguished panel, I want to commend the Special Committee on Aging for its involvement in this issue. I hope that with congressional committees and the administration's task force on Alzheimer's disease working together, Alzheimer's disease will someday be conquered.

Chairman Heinz. Thank you for a truly excellent statement. We are honored to have you as our first witness.

I will turn the floor over to Senator Pressler for questions.

Senator Pressler. I just wanted to say that I commend you for your statement, and the estimates that you have given are conservative estimates, yes.

My staff estimated 2 million persons suffer from Alzheimer's and 120,000 persons die each year. This disease now costs society an estimated $26 billion annually, not estimating loss of productivity.

Also, the prospect for the future are staggering, as experts predict that in 40 years there will be 43 million persons age 65 or older, or nearly double today's elderly population. That is when the crunch comes.

If that occurs, without finding solutions, we are talking about, in today's dollars, $50 to $60 billion. I just want to commend you as a member of the Appropriations Committee. You have said it well here. If we could find a link on this disease, we could save literally billions of dollars in health care costs.

Senator D'Amato. It is kind of like the environmental questions. We are now seeing statements, in making cost estimates, that the dollars spent in preventing, whether it be the contamination of our freshwater drinking supplies, will eventually give us a savings o anywhere from 20 to 40 times that dollar. Those are very, very minimal costs.

I would suggest that the dollars we spend here in research, not to mention the human tragedy, loss, suffering—suffering that takes place with the family, which is so disheartened to have to commit someone to a nursing home; the economics of the situation will pay dividends thousands of times over.

It is the best kind of investment we can make. That coming from a fiscal conservative, you know, my career somewhat, and as I have indicated to you, I look forward to working with you, to see that this becomes the law when we go back to Washington.

Thank you very much.

Chairman HEINZ. Thank you. Our next witnesses are Dorothy Kirsten French, Peggy Morscheck, and Peter Strauss. Will they please take their places at the table?

I would like Dorothy Kirsten French to be our first witness. We welcome you to the committee and thank you for having come a very long way indeed. I think we are all very eager to hear what you tell us.

STATEMENT OF DOROTHY KIRSTEN FRENCH, LOS ANGELES, CALIF.

Mrs. FRENCH. I am an opera singer. My professional name is Dorothy Kirsten. For 28 years, I have enjoyed a very happy marriage to John Douglas French, a prominent neurosurgeon, cofounder, and director for over 20 years, of the world-renowned Brain Research Institute, UCLA.

My husband has Alzheimer's disease.

What a supreme irony that he should be stricken by a disease of the brain, to which he has devoted all his medical years.

With this particular disease, there seems little hope for prevention and cure for our generation, but we had better get busy to help the next generation. In fact, Alzheimer's disease is the fourth most common cause of death in the United States. One family out of three will see one of its members succumb to this horrible disease.

There are 2 million people with Alzheimer's in our country. That is not counting the ones who are hiding it just as I did.

When the doctors told me that Jack had Alzheimer's, I could not believe it nor could I accept it. It took months for me to lose all hope and finally resign myself to the fact that he was never going to get better, but would only go downhill, step by step, losing one faculty after another.

He, who had been the author of 98 important medical publications, could no longer write, nor could he read. I watched him wither as he lost his ability to drive, to work, to golf, and to enjoy our lives together.

I am convinced that he suspected what was happening to him from the very beginning, because we discovered published material on Alzheimer's disease hidden in his desk.

The emotional upsets have been terrible. Jack puts his arms around me and cries. We both fall apart. I know now that I will lose him. While he was still walking to his office, I would put a card in his pocket with his name, address, and telephone number. He was lost twice. One time he walked several miles to a house we had lived in years ago. We knew then that he would have to have someone with him at all times.

Persons with Alzheimer's disease must be supervised on a continuous 24-hour basis. Sports have always been an important part of Jack's life. Now it means nothing. He seldom shows interest in television. When I finally decided to go public, after hiding our agony for months, I gave an interview which appeared in the Los Angeles Times. It generated an intense response. Within 2 weeks, we received 200 letters. Almost 100 percent of these people had members of their family afflicted with this disease.

May I read a very short letter, which gives you an example of the kind I have been receiving.

> DEAR MRS. FRENCH: Bless you for your candor. My own life is so much easier to bear since your article. My mother is 76 and lives with us, and now at least I have a name for what I am dealing with. It helps so very much to relieve the inner tension and pain, and to help me to grow in compassion for her.

Many of these victims were said to be brilliant minds—lawyers, doctors, successful businessmen, and, like my husband, fit individuals. It is up to us to bring purpose to the loss of these great minds.

Jack is still at home with nurses around the clock. His doctors tell me he could live for 10 or more years. As long as he knows me, I will try to care for him at home. There is nothing more I can do for my husband, but in order to help others, I am eager to join the fight in combating this horrible disease.

Consequently, as a tribute to my Jack, I have formed the John Douglas French Foundation for Alzheimer's Disease.

Gentlemen, it is my great hope that your committee will encourage and support research work on the changes in the brain that lead to this catastrophic illness.

Colleagues of my husband are doing research which already show promising leads.

The other very important way in which your help is desperately needed is relief for the families going broke. Three nurses around the clock, LPN's, licensed, cost $288 per day, $8,640 per month, $103,680 per year. If patients need only practical nurses, costs are $198 per day, and $73,000 per year.

How many friends do you have who can stand that kind of cost, and for how long? In my opinion, there should be medicare funds available for the home and hospice care of patients with Alzheimer's disease. Retirement benefits are far too minimal to meet the cash outlay for nursing.

Thank you, Senator Heinz, for inviting me to appear before your distinguished committee. I only hope I have succeeded in explaining how desperate the need is for your help.

Chairman HEINZ. I think you have succeeded beyond words.

Mrs. FRENCH. Thank you.

Chairman HEINZ. I also want to welcome you belatedly back to New York. You sang for many years with the Metropolitan Opera.

Mrs. FRENCH. Yes; 34.

Chairman HEINZ. I was not going to mention the number of years.

Mrs. FRENCH. I do not mind.

Chairman HEINZ. You have a splendid following in this city to this day. I am sure many of the people in the audience welcome you back but are sad that you have come back under these circumstances.

I thank you for what is a truly moving account of just one experience with Alzheimer's, with a loved one. When you multiply somewhere between 1 and 3 million families, that being the number of people who are believed to be afflicted. We do not know. The disease is not well understood, as Senator Pressler has explained.

I recently lost a great aunt who may well have been afflicted with Alzheimer's disease for the past 10 years. She was not diagnosed with having it or not, as the case may be.

I think people will begin to get some idea of the human and emotional toll it takes on the people who love the afflicted, as you clearly loved your husband.

We want to commend you on having formed the foundation. Anybody who is interested in that, I trust and hope they will take cognizance of it.

I happen to have some questions for you, but will ask our other witnesses to speak. Then I will return to you.

Thank you again for what is not an easy thing to do, to tell it not only like it is, but how you feel it is.

[The prepared statement of Mrs. French follows:]

PREPARED STATEMENT OF DOROTHY KIRSTEN FRENCH

I am Dorothy Kirsten French. I'm a professional singer who has sung at the Metropolitan Opera for 34 years. Radio, television, and motion pictures have also been an important part of my career. For 28 years, I have enjoyed a very happy marriage to John Douglas French, a prominent neurosurgeon, who was the cofounder and director for over 20 years of the Brain Research Institute at UCLA.

My husband has Alzheimer's disease.

What a supreme irony that he should be stricken by a disease of the brain, to which he has devoted all his medical years.

With this particular disease, there seems little hope for prevention and cure for our generation, but we had better get busy to help the next generation. In fact, Alzheimer's disease is the fourth most common cause of death in the United States. One family out of three will see one of its members succumb to this devastating disease.

I have enjoyed a beautiful marriage of 28 years with Jack French, and we have both worked very hard in our professions. Our careers separated us much of the time. Now, when we could be enjoying our life together, this hellish nightmare is destroying us.

I watched him wither as the things he loved best were taken away from him one by one—his work, his car, golf, and the life we used to have together. It was difficult to explain to him why he could not drive anymore. He would go to his office every morning as usual but would come home early, seemingly exhausted. At home, he would sit at his desk for hours shifting papers, not really accomplishing anything. So many times we would find him bent over his desk holding his head, emotionally upset. It was shortly thereafter that we discovered he had hidden in his desk published material on Alzheimer's disease. I am convinced that my husband suspected from the beginning of his memory loss that he was one its victims.

Jack was a strict disciplinarian about his weight, and as a golfer, loved to walk. Knowing exercise was good for him, and since he could no longer drive, I urged Jack to walk to his office. It was less than a mile and a very simple route. Fearful that he could lose his way, I would put in his pocket a card with his name, address, and telephone number. Even though that seemed to give him a feeling of security and the independence he needed, he was lost twice. One time he had walked several miles to a house we used to live in years ago. Fortunately, the gardener recognized him and brought him home. We realized then that he would have to have someone with him at all times.

I have been trying to recall when Jack's illness first began but that is difficult. At least 4 years ago I noticed my husband was becoming very forgetful. He began to lose things, forget my birthday, our anniversary, and the little things which become so important to people in love. But I had not the slightest idea that he was becoming seriously ill, and often teased him about being the "absentminded professor."

He worked so hard to keep his terrible secret, that I was almost the last to know that he was ill. This brilliant man could not believe himself what was happening to him.

When I was first told that my husband had this dreadful disease and there was no hope, no cure, but only slow deterioration of his brain, I could not accept it. I pleaded with his doctors to do more tests. Now, of course, all the familiar symptoms are there. He hardly utters three words which make sense. He, who had been the author of 98 important medical publications dealing with the brain, can no longer write. Nor can he read. He is completely incontinent, this very private man whom I knew to be so fastidious. He sits and holds his head repeating, "it's no good."

Jack constantly wanders around our home with his nurse following him to keep him from hurting himself. He has the desire to turn on the gas stove, open every faucet, and pull at the doorknobs. He opens a door as though looking for someone.

Sports have always been very important in my husband's life, but now they mean nothing to him. He seldom shows interest in television. Physically, his doctors say he has a young body for a man of 71 years. The brightest moments of his day are when food is put before him. He is always hungry and it's not easy to satisfy his appetite.

It is necessary to have nurses around the clock to care for him. He is perpetual motion between his medications. Persons with Alzheimer's disease must be supervised on a continuous 24 hour basis.

Senators, what can you do to help in this dreadful problem?

I was still singing at the Met occasionally in 1979 and well into writing my memoirs. Jack was editing for me, before the material was sent to Doubleday, and he was wonderful. At the same time, he was writing the history of the Brain Research Institute at UCLA. I have often wondered if the pressure of all he was trying to do at that time was too much, for shortly thereafter he seemed to completely lose his touch. He would carry the same papers back and forth to his office but had written no new material for days. About this time, we received a notice from the bank that Jack was overdrawn. In looking over his checkbook we found many mistakes; some bills had not been paid while some were paid twice. It was then that I coaxed him to let my secretary take over those responsibilities. His writing had deteriorated so much that it was difficult to read his signature. Following this crisis, we discovered his inability to count money. Jack could not tell the difference between a nickel and a dime. I worked with him each morning trying to jog his memory, showing him over and over that 2 dimes and 1 nickel make 25 cents. It was futile and so crushing to him. He visited a therapist at the university several times a week who tried to recover his reading ability, which was disappearing rapidly. Those were horrible, painful days for my Jack. He would look at me as though wondering if I was aware of what was happening, then suddenly would put his arms around me and we would both be dissolved in tears. Never have we mentioned Alzheimer's disease to each other.

The interview which appeared in the Los Angeles Times on July 19 of this year, when I decided to "go public," after hiding our agony for months, generated intense response. The newspaper, within 2 weeks had received nearly 200 letters, 90 percent of which were from spouses and families whose members are afflicted with Alzheimer's. Most of these victims were brilliant minds—lawyers, doctors, successful businessmen, and, like my husband, physically fit individuals.

I have set aside my career so I can be with Jack and care for him, but our lives seemed to have no purpose. I was feeling extremely sorry for myself and for Jack, until suddenly it occurred to me that though I can do nothing more to help him, I can do something to help others in fighting this catastrophic ailment.

Consequently, I have formed the John Douglas French Foundation for Alzheimer's Disease as a tribute to my husband.

It is up to us to try to bring purpose to the loss of these great minds.

Distinguished Senators; my heart goes out to you for trying to be of help.

Chairman **Heinz**. Our next witness is from Philadelphia, and I take some parochial pride in introducing Peggy Morscheck, coordinator of the Greater Philadelphia Chapter of the ADRDA—Alzheimer's Disease and Related Disorders Association. It is one of the many chapters springing up around the country as Senator Pressler indicated earlier today.

May I add that Ms. Morscheck is a former director of Services for the Elderly and the Blind, Philadelphia, a member of the National Association of Social Workers, National Council on the Aging, and National Gerontological Council of America.

STATEMENT OF PEGGY MORSCHECK, ARDMORE, PA., COORDINATOR, PHILADELPHIA CHAPTER, ALZHEIMER'S DISEASE AND RELATED DISORDERS

Ms. MORSCHECK. Thank you for this opportunity to speak to you and to convey several ideas to you. I think it is important, given the numbers of families affected, and given this is a disease which has, as yet—we have not discovered a cure or treatment for it—to find out what the needs of the families are, and how those needs can be met, other than research. So the role of chapters is very important in that.

I also appreciate the opportunity to represent my profession and provide a little bit of information about the role that social workers can play in serving the families of people with Alzheimer's disease.

I am the coordinator of the Greater Philadelphia Chapter of the Alzheimer's Disease and Related Disorders Association, 1 of 79 chapters throughout the Nation, with an anticipation of having about 100 chapters by the end of the year.

I am a social worker with 10 years of experience working with the elderly and their families. I am the daughter of an 83-year-old woman, who, 3 years ago was thought to have Alzheimer's, until we went through a 5-day diagnostic process, where it was found she had a reversible cause for her symptoms that appeared to have been Alzheimer's.

ADRDA of Greater Philadelphia started about 3 years ago this month, and started with three families getting together whose relatives had Alzheimer's disease.

At that time, they grew very swiftly indeed. We have a mailing list of about 2,000 individuals, two-thirds of whom are family members, one-third of whom belong to various professions and are paid givers of a variety of professions.

Every month at this point, for the last 6 months, we have gotten about 200 new requests for assistance from family members, in regard to Alzheimer's. Functionally, or in fact, we started out to cover not much more than five counties of southern Pennsylvania. We now respond to the needs of both professional and family members in the eastern third of Pennsylvania, central and southern New Jersey, and northern Delaware. We anticipate continuing that kind of support and response for the next year or two, while we concurrently work very hard to help people in those areas develop family support groups and develop chapters belonging to national ADRDA.

At this time, it should be noted that neither Delaware nor the State of New Jersey has a chapter whatsoever. Pennsylvania has two, belonging to ADRDA; Ohio, seven; Virginia, four, with four more coming into chapter status very soon.

The chapters share with national four different goals: They include family support and service, and I think that my board, which is totally made up of family members at this point, would say that is what I should underscore, the more important goal for us.

Education is a goal as well. Research, support of research, as well as public awareness or avoidance, if we are allowed to say that word.

The goals are met by our particular chapter. What I say is representative of our chapter, specifically, reflecting what some other chapters may be doing—some may be doing more or less. We have monthly chapter meetings where anyone is available to come. The purpose of the meetings is education, information, and providing support.

Counseling and information by referral given by phone. Our chapter has decided not to provide any direct hard services, but rather to emphasize the linking agency between the individuals, families, and those existing services that are already present in the community.

So we refer to the services available through the aging systems, mental health systems, and health systems. I think we are helping them to find what some of the gaps are in their services as well.

We also refer to our approximately 30 local family support groups around the area we cover.

Last year, at this time, there were about 5 family support groups; there are now 30. You can see the growth, both in numbers and numbers of support groups, is phenomenal. We produce and distribute a bimonthly newsletter. We send an information packet to each individual who contacts us regarding Alzheimer's.

We spend a great deal of time providing inservice training programs for staff at hospitals, nursing homes, and home health agencies around the area.

We have found that it was not enough to provide assistance to families; we needed to provide assistance to people serving the families as paid caregivers, whether in the home, community setting, or institutional setting.

We also sponsor conferences and seminars. And we do, just skipping on, since time is running, emphasize trying to service the approximately 50,000 individuals in the Greater Philadelphia area who are estimated to be afflicted with Alzheimer's, and more than 100,000 of their friends and relatives who are also affected by this disease.

Two specific needs have come across to us that we need to share with you; one of them—more available multifaceted diagnostic centers. This is a disease that is not easily diagnosed. It cannot be diagnosed by any single service. One must have a comprehensive diagnostic process, including a good physical examination, which pays attention to nutritional status and habits, as well as to the amount, number, and kinds of drugs taken by the individual; a good neurological workup; and a psychosocial assessment.

Without the results of all three of these types of tests, one may misdiagnose someone, and, as in my mother's case, not find they had a reversible cause for the disease or symptoms they exhibited.

There are six of those centers in southern Pennsylvania that can do this kind of work. There is not another one between Philadelphia and Harrisburg, and the middle of Pennsylvania has no centers to go to.

I am sure that is true in many parts of the country. That doesn't take a great deal of money, but it takes coordination of the already existing health, mental health services we have available to us.

Second, we do need more in-home care, particularly respite care—companion care, high-quality, well-trained, not necessarily with many degrees, but well-trained, effective companions who go into the home and provide respite for several hours a day, 1 or 2 days a week, so the individual caregiver in the home can get a break.

Chairman HEINZ. Although you did not put them into the record, your prepared statement has three specific examples in it of people, Mrs. Jones, Mr. Smith, and Mr. Green.

Ms. MORSCHECK. Thank you. The other respite care would be adult day care. We have, in our area, almost enough adult day care facilities to handle the need. Our problem is that the staff of the facilities are not capable of dealing with the Alzheimer's patient.

We need staff training and financial assistance to allow families to purchase that service of adult day care, where in our area costs anywhere from $15 to $37 per day, again within a community allowing a person to have a break or to go and work.

One other aspect I would ask, that this has to be investigated. It seems to me the boarding homes are a possible resource for Alzheimer's patients that had been ignored and not fully developed. If people need total personal care, but do not need nursing care, boarding homes can provide this care. However, the personal care boarding home regulations in our State and many States nationwide are such they cannot care well for these people. You are supposed to have good access in and out of a home. If you allow that, Alzheimer's patients will wander and become a danger to themselves. One needs to have a variation in those regulations allowing someone to put a fence around the facility and allow the patient to wander within a constricted ground. That is an example of several modifications that, if made, would provide a whole new resource for housing of these individuals when they can no longer be cared for at home.

Thank you.

Chairman HEINZ. Thank you very much.

[The prepared statement of Ms. Morscheck follows:]

PREPARED STATEMENT OF PEGGY MORSCHECK

Mr. Chairman, I thank you and all the members of this committee for the opportunity to present the needs of families of those individuals who have Alzheimer's disease, along with the role that chapters of the national organization, Alzheimer's Disease and Related Disorders Association [ADRDA], can play in meeting those needs. I also appreciate the opportunity to represent my profession by sharing with you the role social workers can play in working with chapters and assisting families.

I am the coordinator of the Greater Philadelphia chapter of ADRDA, a social worker with 10 years' experience in working with the elderly and their families, and the daughter of an 80-year-old woman, who, 3 years ago appeared to be suffering from Alzheimer's disease or some other form of chronic organic brain disorder.

I will first define an ADRDA chapter and describe our particular chapter's goals, activities, and planned future role. Then I will present my personal and professional ideas about the services which a social worker can provide within the context of an organization that began as a self-help group and remains fundamentally a lay person/family oriented entity. I will then delineate the needs of the family members of our chapter.

GREATER PHILADELPHIA CHAPTER, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION

ADRDA of Greater Philadelphia is one of nearly 80 chapters throughout the United States belonging to the national Alzheimer's Disease and Related Disorders Association. It began just 3 years ago this month at the instigation of a dynamic older man whose wife was the victim of both Alzheimer's disease and multi-infarct dementia. The chapter has grown from its initial gathering of three family members attending the first meeting to a mailing list of approximately 2,000 individuals. Of those 2,000, approximately two-thirds are family members or friends of someone who has Alzheimer's disease or a related disorder; the remainder are professionals, such as physicians, nurses, social workers, as well as paraprofessional care providers. Some 200 additional inquiries and requests for information and assistance come to the chapter each month, by mail and telephone, via local referrals, as well as referrals from national ADRDA headquarters in Chicago. While the geographic area initially defined for ADRDA of Greater Philadelphia was only slightly larger than the five counties of southeastern Pennsylvania, this chapter now functionally responds to the needs of individuals residing in the eastern third of Pennsylvania, central and southern New Jersey, and northern Delaware. It is anticipated that our area of responsibility will shrink within the next couple of years as new chapters develop in other parts of Pennsylvania, and chapters begin to appear in both New Jersey and Delaware, neither of which has chapters at this time.

National ADRDA and all of its affiliated chapters share four primary goals: Family support and service, education, research, and public awareness. The Greater Philadelphia chapter of ADRDA strives toward meeting these goals through the following activities—which are representative of, but not exactly identical, with all the other chapter's activities:

(1) Family support and service

The chapter office is located in Ardmore, Pa., a western suburb of Philadelphia. It maintains a telephone which can be called from early morning till late at night. Through this number, individuals can be linked with chapter staff, officers, and volunteers who can provide counseling, information about Alzheimer's disease, referral to appropriate existing agencies and organizations, and sympathetic understanding from someone who has been going through similar experiences to those of the caller.

Chapter meetings are held monthly and are open to all interested individuals. Three out of every four meetings provide speakers on subjects of interest from the fields of medicine, psychology, law, social services, finance, etc. The fourth meeting in the series is an open forum, allowing the informal sharing of concerns and suggestions.

ADRDA of Greater Philadelphia is affiliated with nearly 40 local, neighborhood family support groups, in which 8 to 20 relatives of Alzheimer's victims gather together once or twice a month to discuss mutual problems and to share experiences and helpful ideas for coping. These groups may be total self-help groups or may be assisted by an agency or organization. Referrals to appropriate family support groups and the encouragement of the formation of such groups are important functions of this chapter.

A chapter newsletter is produced and widely distributed every other month, containing summaries of information from speakers at chapter meetings, practical coping suggestions, listings of established and newly forming family support groups, reference and resource suggestions, and other pertinent useful ideas and information. Meeting announcements are mailed on alternate months.

(2) Education

Individuals contacting this chapter for the first time are sent an information packet, which contains several items, including a bibliography from which articles, books, and pamphlets on Alzheimer's disease can be ordered. The chapter is also a major distributor of "The 36-Hour Day," an excellent handbook for families caring for individuals suffering from this disease.

Chapter staff and volunteers are available to do presentation on Alzheimer's disease to community groups, family support groups, professional organizations, college, medical and nursing classes, and personnel of hospitals, nursing homes, and home health agencies. Video and audiotapes, as well as slides, are used in these presentations.

The chapter also sponsors and participates in conferences and seminars geared to both family and professional interests about the disease.

Education of the general public is provided through news releases to the media, public service announcements, and periodic participation in radio and television programs.

(3) Research

The chapter supports medical research on the local and national level through financial contributions, and by providing information and encouragement to researchers. Efforts are made to keep chapter members aware of the research efforts going on both locally and nationally.

(4) Public awareness

ADRDA of Greater Philadelphia encourages legislation for increased medical and social benefits to Alzheimer's disease patients and also works to increase the availability and accessibility of already existing community-based services. The chapter also testifies at governmental hearings on the local, State, and national level regarding the needs of Alzheimer's disease patients and their families. Both public awareness and education goals dovetail when the chapter attempts to increase the availability of services by educating paid caregivers about noncostly ways to provide their services to our specialized population.

THE ROLE OF THE SOCIAL WORKER IN A CHAPTER

As the rapid growth in the numbers of participants in our chapter illustrates, an ADRDA chapter can find the demands for its services quickly outstripping the capabilities of its originally family-member volunteer "staff" to meet those demands or needs. Such was the case with this chapter. After considerable study and with a good deal of trepidation, the all-family member board of ADRDA of Greater Philadelphia decided last November to hire a part-time social worker on a consultant basis, to act as chapter coordinator. At that same time it was decided that those services described above would comprise the activities of the chapter, with the concomitant resolve that the chapter would not become involved—at present and in the near future—in providing any direct, "hard" services. It should be noted that all but one of the officers and board members of ADRDA of Greater Philadelphia at this time were in their sixties, worked full time, and had spouses suffering from Alzheimer's disease residing in nursing homes. While not all ADRDA chapters will have such older and overextended leadership, this kind of leadership is not unusual.

It is estimated that within the Greater Philadelphia area, there are approximatley 50,000 people who have Alzheimer's disease, and at least an additional 100,000 individuals, such as family members and friends, whose lives are directly affected by the impacts of the disease. The implications of this crisis of need and crisis of growth for the chapter is the need for paid staff to handle many of the mechanics of chapter operation. Essentially, a social worker hired to assist an ADRDA chapter must be a combination expediter-counselor-planner-administrator-community organizer-educator-and-social caseworker who can manipulate the environment on behalf of family members and their loved ones. This multifaceted role lends itself well to the profession of social work, with its emphasis in training upon problem-solving and enabling. It should be noted, however, that this role is appropriate only for that transitional period—however long or short that time may be—during which a chapter is still young and growing, just evolving from an overgrown family support group to what may become in the future, a well-established, fully staffed agency on the local scene.

Social work training seems to enhance the desires of family members in a variety of ways. Most important perhaps is the emphasis in social work upon (1) the importance of the individual, no matter what state he or she is in—the insistence upon upholding the value and human dignity of each person, no matter how impaired; and (2) the principle of helping individuals to help themselves to maintain as much independence as possible, for as long as possible, no matter how impaired. These two principles have emerged as the underpinnings for all the work done by ADRDA of Greater Philadelphia.

A major cautionary note should be mentioned here, to preclude misunderstanding. It seems not only desirable but also absolutely appropriate that in all such organizations, such as ADRDA chapters, family members should maintain the ultimate control, with policymaking authority firmly in the grasp of lay leaders. The social worker can and should provide information, advice, expertise in expediting the policies, but that social worker should also remain accountable to a board dominated by family and other lay persons. Otherwise, the danger is too great that "professionalism" could overwhelm the vision and needs of family members and develop its own goals.

Interestingly enough, it has been my experience that many, if not most, of the professionals who have become deeply involved with the workings of ADRDA chapters and family support groups have compelling personal/family experience with the disease or its related disorders. They bring a particularly clear insight to their endeavors.

MAJOR PROBLEMS AFFECTING AD FAMILIES

The following case studies, taken from calls and letters received by ADRDA of Greater Philadelphia from family members with relatives suffering from Alzheimer's disease, are perhaps the best way to introduce the problems encountered by many, many families.

1. Mrs. Jones, age 57, has been caring for her mother, age 78—a victim of Alzheimer's disease—at home for the past 3 years. Her mother has been bedridden for the last year. Until this past December, Mrs. Jones, along with her elderly father, had been caring for the older women with no outside help. At that time she finally had to hire a helper for 30 hours per week, at $4 per hour, to augment her own efforts. The mother sleeps in a hospital bed set up in the kitchen and attached to a winch connected to the ceiling, so that it can be raised at one end, since the mother has an impaired hip and cannot have her bed cranked up and down. The helper will have to increase her hours now, as the older woman nears her last weeks or months in the terminal stage of Alzheimer's disease. The cost for the helper is split between Mrs. Jones, her husband, and her father. Additional expenses have been the $300 suction machine which is necessary to keep the older woman from choking as she attempts, unsuccessfully to swallow food or liquid, and the 4-inch thick eggcrate-type foam mattress placed over the bed which cost $90 and will soon need replacement.

Mrs. Jones realizes that her mother is going to die soon and insists on keeping her promises to her mother that, (1) she would not be placed in a nursing home, and (2) she would not have to die in a hospital setting with all kinds of tubes attached to her. Mrs. Jones' primary concern now is that she do all possible to keep her mother comfortable as she declines. She is proud of the fact that her mother has never had a bed sore—she is turned every hour, and her feet rests in a hollowed-out depression in the mattress to avoid rareness on the heels.

Despite all her valiant and creative efforts to insure her mother's comfort, Mrs. Jones is almost frantic with anxiety, frustration, and resentment. She describes her life during the past 3 years as "a living hell"; recounts that her husband is remotely supportive but has taken to living most of his life in their motor home parked on the lot, in order to avoid the distress of the house situation; claims that the pressure on her and her sister—who relieves her on 2 weekends a month has ruined their formerly close relationship. She also refuses to allow her grown daughter to help out, not wanting to impose on her family relationship. She has made her husband and daughter promise that they will simply place her in a nursing home and visit her twice a week, should she ever be so impaired in later years.

2. Mr. Smith, 60-plus, is a retired business executive who has vowed to care for his wife at home, no matter what. In order to accomplish his goal, he has had to go back to work after having retired from his career position. The extra money is needed to pay for the medicines and aides she requires, but is also used to reimburse one of his daughters who has temporarily given up her career as a schoolteacher in order to stay home and care for her mother during the days. Mr. Smith cares for his wife in the evenings and over the weekends. Another daughter helps out from time to time as she is able. This arrangement seemed the most feasible after Mr. Smith totaled up the cost to him if he hired outside help to come into the home. It certainly involves considerable sacrifice on the one daughter's part.

3. Mr. Green's wife has now been in a nursing home for 3 years, but before that time there was a long period when he kept her at home, without supervision for the hours that he was out working. However, he was able to work out an arrangement with his employer during that time to have flexible hours. He went to work at about 5 a.m., returning at about 7 a.m. to dress and feed her; went back to work till noon, when he returned to feed her lunch; returned to work till dinnertime. Following this extraordinary schedule, he was able to keep his wife home with him fully 3 years beyond the point when his physician had suggested Mrs. Green be placed in a nursing home. At that time, in 1979, Mr. Green had compared costs of $40 a day for an in-home aide with the then-cost of $39 a day for nursing home care. He finally had to place Mrs. Green in a nursing home when she began to act out and to wander too much. He currently pays approximately $58 a day for the nursing home care, and Mr. Green can be found at the home every day at dinnertime, feeding his wife who no longer can speak and no longer recognizes him. Back in 1979, and earlier, there were no adult day care programs in existence in Mr. Green's area, so he was forced to improvise his solution for care.

It may be seen from these examples that affordable home care of high quality is a major need for Alzheimer's disease families. This care would comprise the services of nurses, therapists, medical social workers, homemakers, aides, home-delivered meals, and physicians who make house calls. While many of these services exist in our various health and aging systems, most of them are not reimbursable under medicare because Alzheimer's disease does not fit the criteria for medicare coverage (i.e., short-term and improvable conditions). Paying for these services directly out-of-pocket for months and months is prohibitive. Few families can manage it at all; as a result, they place enormous stress upon themselves and all the members of the larger family unit, sometimes to the point of destroying their own health. It should be noted that medicare is not even a temporary resource for the many Alzheimer's victims who are in their forties and fifties. Any solution to this problem should address not only the Alzheimer's disease victim's needs for long-term chronic care within the home and the community, but also the similar needs of the entire chronically ill/impaired and frail elderly population. The service management model used in area agencies on aging should be extended to work with such families more frequently and thoroughly, and the hospice model of care should be seen as a reasonable prototype for care to these individuals who are indeed terminally ill, but who often take years to deteriorate to the point of death.

Respite care is also a major need for families caring for the Alzheimer's disease patient. Residential/short-term institutional respite care should be available so that family caregivers can truly get away for a full week or two at a time, to deal with family business, or to become fully refreshed. Companion care provided in the home by staff trained to deal effectively and humanely with the Alzheimer patient is most needed for 3 to 4 hour breaks once or twice a week. The availability of adult day care geared to meet the needs of the Alzheimer's disease victim would allow more family members to care for their relatives at home while still keeping their necessary employment. Currently, in southeastern Pennsylvania, there are about 15 such programs, but some do not accept Alzheimer's disease patients, others do not accept anyone under 60, still others accepted Alzheimer's disease patients but only if they are not confused, do not wander, and are continent—in other words, they functionally refuse the Alzheimer patient. Costs for adult day care vary in this area between $15 and $37 per day, and there is no program that provides even a little financial assistance to the families in paying for this service. One idea might be to develop adult day care models which include a cooperative component, where costs of operation are reduced by family members contributing their respective skills on a limited but regular basis.

More comprehensive diagnostic centers are needed in order to insure the correct diagnosis of Alzheimer's disease. Since there is no single diagnostic procedure that can identify this disease, it can only be determined through differential diagnosis—the process of eliminating all other possible causes for the presenting symptoms. Thus, a very thorough physical examination with sharp attention to nutritional habits and status, along with a thorough pharmacological workup to determine drug intake and interaction should be performed. Then a full neurological series of tests should be done. Finally, a psychosocial assessment should be performed. Only when the results from these types of tests—the physical, neurological, and psychosocial—are combined can a reasonable conjecture be made to diagnose Alzheimer's disease. Within southeastern Pennsylvania there are six diagnostic centers which do such a combined total assessment. Harrisburg, 2 hours to the west of Greater Philadelphia, is the next such center, and much of the rest of the State has no access to such thorough diagnosis at all. One of our fears is that Alzheimer's disease will become a popular and "easy" diagnosis for physicians to make: The scene could be that a physician sees an elderly person who is confused and has a very poor memory and assumes that the symptoms must be caused by Alzheimer's disease, when in fact, there are more than 100 possible causes for symptoms that look like this disease—and some of them are reversible.

Many Alzheimer's disease victims have difficulty being placed in nursing homes when there is no family, or the family can no longer continue to provide the extensive care as they have for years. This is because, while an Alzheimer's patient may need total personal care with feeding, bathing, dressing, toileting, walking, and must be constantly watched because of wandering and high levels of anxiety, he or she may still not qualify for intermediate or skilled nursing care. If they once are placed within a nursing home, they may find it impossible to ever qualify for medical assistance because Alzheimer's disease is not listed as a reimbursable disease. In some cases, physicians list another condition as the primary illness, and thereby assist the individual to become eligible for assistance.

ADRDA of Greater Philadelphia applauds the establishment of a national task force on Alzheimer's disease because family members have an unquenchable desire to learn as much as possible about research into this disease and to encourage the expansion of all varieties of Alzheimer's disease research. Chapter coordinators are often deluged with inquiries about new possible treatments, long before their own local or national ADRDA's medical and scientific advisory committees have had a chance to review the more recent research. The hunger for answers regarding the cause, possible treatments, and possible cures for this devastating disease is enormous.

Finally, it would appear to be necessary to modify the personal care boarding home regulations and guidelines nationally, and in the States, in order to make such sheltered living situations more appropriate for Alzheimer's disease victims. The boarding home could be the most appropriate residential situation for a patient for months, if not years, if proprietors were allowed to fence their properties in order to allow Alzheimer's disease patients free space within which to walk but protection from wandering off the grounds. Regulations could be modified to allow such facilities to lock off the sleeping quarters, except for a designated nap period each day, thereby reducing the opportunity for disruptive wandering and unnecessary sleeping during the day that makes night wandering more likely. Other such modifications would allow some proprietors to specialize in serving this population well.

Thank you for your attention.

Chairman HEINZ. We have heard from a member of a family of someone afflicted by Alzheimer's; we have heard from a community support organization, aimed at trying to assist people in their homes and communities. We will now hear from a legal expert, Peter Strauss, whose law firm, I am told, specializes in the legal problems, and there are many, of the elderly and of the indigent, but most especially, the elderly, and those who are not in complete command of all of their mental faculties.

Mr. Strauss, I am aware of your considerable and unique expertise in this area. I commend you for it as a most unusual area of the law in which to specialize. I think we are all eager to hear your testimony.

STATEMENT OF PETER J. STRAUSS, ESQ., NEW YORK, N.Y.

Mr. STRAUSS. Thank you. It has been a fascinating change in my life, which started about 3 years ago, when more and more of my clients began speaking to me about the problems of their elderly parents, spouses, or brothers and sisters. I saw there was a real need in this city, and probably around the country, for some attorneys to begin to focus on the special problems of the aging.

It has broadened its scope beyond that, of course, obviously, to deal also with problems of disabled children. The issues are very similar.

At a time when you are trying to bring a ground swell support for your very worthy views on research funding, and I think that will happen, I want to play the role of gadfly, and pick up on Mrs. French's points, very briefly touched on in her statement concerning the devastating economic consequences of Alzheimer's disease to the family during the next 10 to 20 years before these massive costs can be cut back by successful research.

I have represented over 500 Alzheimer's families in the last year or so. I have become familiar with the economic devastation that these families face.

Incidentally, whatever I talk about today in terms of Alzheimer's disease, is only illustrative of the problems resulting from many other medical problems which require long-term custodial care.

If a person has a stroke and will need chronic custodial care, that person's family is faced with the same devastating economic facts, yet perhaps does not suffer the emotional trauma.

My typical client is a woman or man, the spouse of an Alzheimer's victim, who comes to me at a time of crisis; a person whose world has fallen apart, who evidences the kinds of feelings that Mrs. French so aptly demonstrated to us today. These people come in and say: "At a time when I am facing this crisis with my family and life, I am also told that I am going to have to be economically devastated. I am told that if I have $150,000 in lifetime savings with my spouse, and perhaps a home, in addition, I must spend down our joint assets to $4,200 or $5,000, depending on State regulations, before my spouse becomes eligible for medicaid—the one program that deals with custodial care."

Think of the irony of this: Medicare, we know, does not cover custodial care; it was not designed for that. It was designed for intensive hospital care and medical coverage for treatable diseases. No insurance policy covers these costs. You cannot buy an insurance policy that covers custodial nursing home care or home health care.

There are a few policies available which give you a per diem amount, such as those sold by Art Linkletter on TV, but the benefits under such policies are a drop in the bucket.

In prior years, when the cost of a nursing home was $1,200 or $1,500 per month, and the family could contribute that cost out of their income, the cost of custodial care was manageable. Today, in this city, nursing homes cost between $3,500 and $4,500 per month.

It is not possible, any longer, unless you are very wealthy or very poor, to manage the system. I am faced with clients daily who come in and say, "Can you help me?"

We have developed a series of strategies. It isn't really important to go into details today, but in general, we are talking about transfer of assets, setting up trust funds, and other techniques, which, if done early enough in time, can put the family in the position to say after 2 years, "I cannot afford it anymore." We perhaps have been able to protect the victim's spouse, so that he or she can hold on to some of their assets and live a decent life. These are not young, healthy people. These are elderly people, 65 and older, who may be ill themselves. They are frequently barely able to function as a couple in the community, without these massive costs.

While you are searching for the answers, while you are seeking the funds to find the medical solution, we must begin to think of some immediate, short-term solutions to benefit spouses of Alzheimer's victims, allow them to continue to hold on to some of their assets and income so they are not wiped out. That may require amendments to some of the medicaid rules; amending the deeming rules; amending the transfer of assets rules. We must provide relief to spouses.

I see greater problems in the cases of married couples than in the cases of single persons. I am less concerned about the economic impact on a person who has to spend all their own funds, and not be able to leave an inheritance for their children, although there is a valid argument that people ought to be able to pass on some funds to their children and grandchildren.

The critical issue, the one we should look at first, is the one of the married couple. Second, begin to look at some of the alternative care programs you will hear about today, by people far more expert than I.

Consider different kinds of congregate care facilities, if they could be developed for the Alzheimer's victim, where a safe and clean environment could be provided. Many Alzheimer's victims do not need the kind of intensive nursing home care a medical facility provides. Then, perhaps, the cost of care could be cut down.

Last, I strongly agree that more home health care needs to be provided. But in the meantime, while looking at these solutions, we must do something about protecting the family from economic devastation. It is a tragedy and one that is a very sad commentary on what we do to the elderly.

Thank you.

Chairman HEINZ. I will note that you abbreviated your testimony. There is much in it worth reading. I think all of it is well worth reading. It will be placed in the permanent record.

[The prepared statement of Mr. Strauss follows:]

PREPARED STATEMENT OF PETER J. STRAUSS

I am an attorney in private practice and a member of the firm of Strauss & Wolf in New York City, admitted in New York and New Jersey. Most of my career has been spent in general practice, with emphasis on estate planning. Three years ago, I found that more and more of my clients were raising problems concerning their aging parents or their elderly spouses, problems regarding the management of their financial affairs and concerning their health care. I began to focus on these concerns, became aware of the dimension of these problems, developed some solutions in appropriate cases, and suddenly found I had become a so-called "expert" in a new and growing field of law—the legal problems of the aging.

It is clear why this happened. The senior citizen segment of our population has grown and continues to grow, and health care costs are rising dramatically. In particular, the costs of maintaining a person in need of chronic care have soared. The cost of skilled nursing facilities in the New York City area runs between $80 to $120 a day, with some of the better homes costing $150 daily.

The problem of the financing of long-term care has become a major issue for this Nation.

My senior citizen caseload falls into several broad categories:

Classic estate planning.

Protective services.

The problems caused by the need to pay for long-term chronic health care—usually care which is defined as custodial.

It is this latter area on which I wish to focus today.

The following typical cases will clearly illustrate this problem.

Mr. and Mrs. O.: Mr. O. has Alzheimer's disease. He recently was admitted to a nursing home. He will never return home. Mrs. O. has cancer. She receives chemotherapy at a New York hospital on an outpatient basis, and resides alone in the apartment she formerly shared with her husband. As Mr. O. became more seriously ill over the years, Mrs. O. had most of the couple's assets, which total about $150,000, placed in her name. Mrs. O., who was worried about how she could pay $40,000 a year for her husband's nursing home expense and still be able to live independently, sought my advice.

Mr. and Mrs. J.: Mrs. J. had been paying for the nursing home for her husband for 2½ years when she came to see me a year ago. She had spent about $90,000 and had $35,000 remaining. She had been informed that she had to spend all her assets before her husband became medicaid eligible. I advised her this was not correct, had her discontinue payments to the nursing home, and apply for medicaid. The medicaid application, initially denied, was approved after a fair hearing decision.

Mr. and Mrs. S.: Mr. S. consulted me recently. Her husband has Alzheimer's disease and is presently living at home with Mrs. S. and two children. In addition to their home, they have about $125,000. Mr. S. is declining, and will soon need full-time care at home. Mrs. S. hopes to be able to care for Mr. S. at home indefinitely, but institutionalization may become necessary. Mrs. S. does not know how she can afford the cost of Mr. S.'s care and still maintain her home and support her family.

Each of these cases poses the same basic issue: Is there any way to provide for long-term care of the patient spouse without impoverishing the spouse living in the community?

In each of these situations I am dealing with a client in crisis. Traumatized by his or her spouse's illness from which there will, in most cases, be no recovery, my client has discovered that there is no financial help to pay for the costs of this illness. The client has learned that medicare will not pay for this kind of care. And the client has also learned that any health insurance he or she might have will also not cover these costs.

There is no private health insurance that I know of that covers the costs of long-term chronic care. Most health policies follow the medicare definitions of "skilled care" and "custodial care," and thus do not cover long-term care of a "custodial" nature.

The heart of the medicare problem, of course, is the limitation to pay only for "skilled care." When medicare was enacted, a policy decision was made to cover only treatable medical problems and exclude coverage for care which was deemed merely "custodial."

When the costs of custodial care were more modest this exclusion was not as serious a problem as it is today. Now, with home health care and nursing home costs running into staggering sums, only the very rich can afford this on their own.

Although there is little benefit provided by private insurance or by medicare, there is, ironically, one program that pays for the costs of chronic, long-term care, even care deemed to be purely custodial, and that is the program known as medicaid.

Medicaid, however, is a program designed for the poor of this Nation. It has, as you well know, resource and income eligibility requirements. Yet, more and more members of our elderly population are asking whether medicaid might be tapped as a resource to assist them in avoiding economic disaster. They have been told that presently all of the resources of the married couple must be used before the ill spouse can receive medicaid. They ask us if there may be a way to qualify without both spouses spending down to the medicaid eligibility level.

This is a remarkable development. Middle-class families, driven by fear and panic, seeking to take advantage of what is essentially a welfare program.

What is needed is a major rethinking of the basic policy which excludes custodial care from coverage. Clearly, having these costs assumed by medicare would have enormous economic consequences. But the problem cannot be ignored. It will continue to grow more serious as costs continue to increase and our chronic care patients live longer.

Chronic care costs must be assumed by the Nation as a whole. There are several methods by which to approach the issue. The medicare program can be amended by adding a new "part C" which would provide coverage for long-term care. A new "title 21," as some of you have proposed, might be enacted. These costs should be approached no differently than those of cancer or heart disease. Absorbing the entire cost, or enacting a system with some more deductibles and coinsurance is a question that can be debated, with honest difference of opinion.

I believe that reform of our existing laws to place greater emphasis on home health care would be economically more sound than our current medicare and medicaid laws which encourage institutionalization. I also believe that serious consideration must be given to the support of new kinds of residential facilities to provide care for persons, such as the victims of Alzheimer's disease or strokes, who do not need the kind of medical support that skilled nursing facilities are designed to provide. These two approaches would, in my view, provide care at lower cost than existing institutions, as well as deliver more appropriate and humane care.

I want to stress again the special problems of married persons where one partner requires long-time care. I have seen too many cases where the community spouse is left without the means to function in accordance with a decent standard of living, because of his or her spouse's illness. I see no ethical justification for this. At a minimum, even if major policy changes are not forthcoming in the near future, the medicaid laws should be amended to create immediate protection for spouses. Perhaps a "marital exemption" concept should be enacted, allowing a community spouse to retain 50 percent of the couple's combined resources, with some minimum "marital exemption" established for couples with very modest means.

It is impossible in this brief statement to cover all of the issues I believe need to be discussed. What I want to stress is that there is a rapidly expanding segment of our population which requires care it cannot afford and for which there is little relief. I see this clearly demonstrated by the clients who come to see us every day, who, out of fear, ask if becoming old merely gives them the right to become paupers.

Chairman HEINZ. Let me begin with Mrs. French. Mrs. French, you, I think, are in a unique position. Could you tell us what are the greatest demands on a person in your situation? Specifically, could you describe the problems that face a spouse trying to cope with a husband, in this case, who has contracted Alzheimer's.

What do you find the single most, from the standpoint of personal care, burden placed upon you or your household?

Mrs. FRENCH. I must say the financial burden is most important. What happens, what happens when it is all gone? It can only go so far? Then what do I do with my husband? Where does he go then?

I have looked at 15 homes because my own doctors said, "Dorothy, you cannot keep this up. This will ruin your health." I have lost 15 pounds. I am working like a dog on this foundation. The places that I have looked at, I would not put my husband in. Alzheimer's disease people should not be, I believe, in a rest home where there are many people all crippled up, poor things, at the end of their life. These kinds of things, to see for an Alzheimer's person, I believe, is very disturbing.

Any little, tiny thing, anything, a word can set them off into a terrific agitation.

When they are agitated it is very difficult to have them at home. They go around the house constantly touching everything, breaking things. No one knows why, and a special strength seems to be in them. My husband is in wonderful physical condition. His doctor said that he wishes he had his body. He has been through two surgeries within the last 6 months. He has bounced back more healthy than ever. Still, there is nothing. He holds his head and says, "It doesn't work, it is no good." That is the most that he can say. The other day he took me by the hand and took me into his sitting room and said, "Dear, I am at your mercy." That tells it all.

Chairman HEINZ. You are, as I understand it, in a position to provide him with round-the-clock care.

Mrs. FRENCH. I am in a position to provide for nurses, practical nurses. We are getting along.

Chairman HEINZ. What, in your judgment, are the most essential services that those practical nurses, or if you did not have practical nurses and could only get some part-time help, home health care, what are the most critical elements of that care? Is it something that gives you a break? Is it to insure that your spouse is not a danger to himself? What is it?

Mrs. FRENCH. He can be a danger to himself easily. We happen to have a swimming pool. He could fall in. I have bought all kinds of things to rescue him if this should happen. He has to be held by the hand. When someone touches him, lightly, and he knows he has a friend, he is calm. If he should walk, for instance, in the street—we had a terrible situation at one time, when I dropped my secretary off to get some groceries. We were on San Vincente Boulevard in Los Angeles, and I said, "I will pick you up. Walk with Jack, he loves to walk."

I parked in back of a car. When they came along, we tried to get him into the car. He did not want to get in, for some reason. A man in an automobile in front of us looked back at us, in astonishment, and ran into a house. He thought we were kidnaping him.

Those kinds of things. We have to place his name on him, when he walks. That did not work out, though.

Chairman **Heinz**. Ms. Morscheck, let me transfer to you and ask, assume that somebody in very similar circumstances to Mrs. French came to you but did not have the financial resources to afford a practical nurse, and was well enough off that medicaid was not available. What would you try and do in similar circumstances?

Ms. **Morscheck**. One of the very first things I would do would be to encourage the family member to contact the local county office on aging and ask for a service manager to help them identify the specific problems they are facing, and then identify the services in the community that might meet those needs. If there were 12 needs identified, we might be lucky enough to come up with seven or eight services that could meet seven or eight of the needs.

There are a variety of programs in some areas that allow people who are of middle income to get part-time assistance in the home, so that the caregiver can have some respite. There is a great deal of need to sit down and talk with the individual about what family resources there are. Not money, but what human resources there are within the family, among the neighbors, from friends, church groups, informal resources they may draw upon to assist them.

A member of our chapter whose husband was stricken by Alzheimer's at the age of 44 quickly took it upon herself to educate her friends, relatives, neighbors, and church members about the disease, and when they called and said, "We are sorry to hear about your husband, what can we do," and she said "I am not sure, but I will get back to you."

She got back to them and mobilized 30 different individuals who come in and spend 1 hour a week with her husband every week. She was able to carry that on for 2½ years, until he deteriorated to a point where he could no longer do as much as he could before.

It takes a good deal of—one is asking a family member who is overextended emotionally and physically to look around and see what else they can manufacturer, can create, out of their informal contacts within the community.

Very often it ends up being a fruitful avenue to pursue.

Is staff trained to do this? Is staff trained to link up those services already available and accessible financially? Then to continue to work in a very creative way, as a constantly creative process, not the easy road to take in any agency, to come up with ways and means to draw upon the local, informal resources to meet some of the needs.

Also, one can encourage folks to do a great deal of advocacy with local decisionmakers to make services more available. That is a long-term project to get involved in. One other thing we do encourage, we are working with our local Red Cross and encouraging them to provide more family members with more training about home care, so people can feel a bit more secure in their own capabilities to deal with care at home. That is assuming they have the ability to stay home and do not have to go to work.

Many of them are overwhelmed by the catastrophic reactions, possibility of seizures. This safety difficulty where people can hurt themselves, break things, or burn themselves on stoves. The local

Red Cross is an agency with a tradition of helping people to help care for themselves. We are trying to help build on that tradition and to provide more information and resources with our family members.

Chairman **Heinz**. Thank you. I have taken a disproportionate amount of time, and I anticipate Senator Pressler and Senator D'Amato have questions for Mr. Strauss.

Senator Pressler. I think the witnesses have spoken very well today. My questions will be brief.

Support groups and legal advice are very important. The support groups have sprung up throughout the country. I am glad to see we have a lawyer here, because so many of the real victims are the families, loved ones, who need someone to turn to for advice.

I would like a little better explanation of how people can get in touch with support groups or with lawyers who are familiar with this. I am glad to know that a field of practice is developing in this area. The real victims are the families, because the person having Alzheimer's disease is very healthy, and feels, in his body, very healthy, but of course suffers from the disease.

The people who perhaps suffer the most are the families and friends. That is something that we need to get across.

If someone wants to get in touch with a support group or with an attorney in this area, what steps do they take?

Ms. **Morscheck**. Maybe I can answer the first part. National Alzheimer's Disease and Related Disorders Association does have an 800 number that can be called. At that time, they will be assured of getting a basic package of information from the national association. They will be referred to a local chapter or a local large support group, if a chapter does not exist. They can call the chapter on their own. If they fail to do that, there is a referral slip that comes from national to each chapter. We make a great effort to try and reach these people within a while. That becomes very difficult, logistically, as we are a small group that has grown quickly.

I currently have 600 green referral slips from national that have arrived on my desk in the last 5 weeks. We are constantly scrambling for assistance, then, in simply dealing with that volume of requests.

Once people make contact with a chapter, we will try to answer any kind of question we have, and we have found in our own area lawyers who can be of assistance. There are some very good senior legal assistance projects that are funded, where you can get free legal advice or low-cost legal advice.

We refer there, as well as to some private lawyers for that help.

Mr. **Strauss**. The legal services programs would be a good source of advice. Although they are restricted to providing legal services to the limited economic levels, they might be a source of information, as were the association groups.

Frequently, also, we get referrals from social workers in hospitals, and they may be a good source of information for the family. The contact point is usually when a family member leaves the hospital and needs placement in a nursing home, and social services institutions can be very helpful at this time.

We found in our own practice that it became a team effort, working with the social work profession. One of my paralegals is a social worker, because of the intensity of client action in these areas.

The bar associations are also very good sources of referrals.

Mrs. **French**. Every Alzheimer's disease patient is different from every other one. They all have peculiarities, it seems. If I ask my husband to receive 10 other people in the house, say, it would bring a seizure on him. It would upset him very much. I notice very often that if there is a change in a nurse, which there has to be, occasionally, there is a very big upset. So I could never have, or I could not ask people, who might be neighbors, to come into my house. There would be no way.

Senator **Pressler**. I would state that I know firsthand what the support groups do. They have only recently been formed.

You mentioned 500 or 600 referral slips. We published our article in People magazine and received so much mail from people across the country, that we had to send out a form letter to answer them individually. You get deluged. I know what all of you are facing.

Chairman **Heinz**. Senator D'Amato.

Senator **D'Amato**. One question for Mr. Strauss. In your counseling of those who have come to you, have you ever had to advise a couple to divorce in order to protect the assets of the family?

Mr. **Strauss**. I have not. I am frequently asked whether that is a solution. It is one of the more painful moments in the client interview, when one of the family members will say to me, "Should my mother divorce my father?"

I usually do not think it is indicated, for a variety of reasons. First, I do not think we usually have legal grounds, at least not in this State, and probably in most others.

Second, I feel the courts, in many cases, are likely to place the same financial burden on the divorcing spouse as they would anyway. We try to come up with solutions other than divorce, to protect the spouse.

Those would involve, for example, some transfer of assets, some creation of trusts, perhaps, or various other things, to try to give the spouse some protection.

I want to make this point, because the issue will come up in your deliberations: Should we allow families to cheat the Government by giving away the money? I was asked that question when I testified before Representative Pepper's committee on August 3, by a Congressman from New York. I said that he had placed the issue in the wrong framework. I have met no husband or wife that was not willing to make some financial contribution to the care costs of their spouse. Nobody wants to cheat the Government. Nobody wants to say, give away the money; wait for the time period; go on medicaid; and say, "Let's get away with it." That is not the motivation.

I have never seen that. It is fear, panic, over being wiped out, that makes them come to us. We are taking these actions from a strategic point of view because we have no choice.

The spouse says, "If I were required to give an amount that I can manage, I will do it willingly." The transfer of assets is a consequence of high costs and the absence of a program that pays for custodial care. It is not something that citizens of this State do because they think they will make money.

Senator D'AMATO. Your suggestion would be then to design a formula that would protect that spouse or family from the total financial ruin. Correct?

Mr. STRAUSS. Yes.

Senator D'AMATO. So there would be a portion, up to a certain amount, of assets or things they would pledge?

Mr. STRAUSS. Something like we do under the tax laws. We penalize married people here. We also penalize people, and this may sound strange, who are not lucky enough to have a disease like heart failure or cancer. If you had cancer, your costs are covered. So, we are penalizing the middle class, penalizing the people unfortunate enough to have Alzheimer's, and penalizing married people.

So I think we have to begin to look to something like a marital exemption, although the limits and scope of such an idea need a great deal of debate.

I realize the vast funding and financial burdens this would create. I am not naive.

I know if we picked up the cost of custodial care, for example, you are going to be assuming the cost of that $22 million. That is not going to happen. Maybe we have to agree to a means test. We may have to agree to a program that is keyed in to what the family can afford.

I do not want to be the judge of where to draw that line, and I know it is not easy for you, but we have to look at a marital exemption of some kind which would allow the healthy spouse to retain a portion of the total assets of the couple, regardless of in whose name these assets may be registered.

At present, the State of New Jersey, for example, does not seek contribution from the community spouse. If all of the money is in the name of that spouse, the patient spouse goes on medicaid and the State does not seek any contribution. On the other hand, if all of the money is in the patient's name, the community spouse gets nothing. This makes no sense. We have to look at some kind of marital exemption system. Perhaps with a minimum. Fifty percent of $40,000 is not going to maintain someone very comfortably anyway.

That is one of the directions we ought to proceed in.

Senator D'AMATO. Thank you very much.

Chairman HEINZ. Thank you. Peter, I have a last question for you: I find your challenge to us, in effect, a new part or new title to medicare, perhaps a means-tested one, with possibly marital deductions of some kind, quite challenging indeed. In addition to that, you, in your testimony and in your remarks, have urged us to be much more aggressive in the whole health care area.

Mr. STRAUSS. Absolutely.

Chairman HEINZ. I think it is fair to say that you endorse some of the initiatives we mentioned earlier.

Mr. STRAUSS. I think your legislation is an important step forward. Clearly, it is just a beginning, but some of those solutions are ones we ought to be following carefully.

Chairman HEINZ. What I find equally intriguing is your third suggestion which tracks, I think, the one Peggy made, to find some kind of institution that is not a nursing home, and probably not what boarding homes are as we know them today to be.

How feasible is that? Have we gotten ourselves in a box where, we want a certified, Alzheimer's-type certified nursing home, but not all of the baggage and regulation that comes along with the Federal Government? We will soon make, if history repeats itself, boarding homes unaffordable if we turn them over to the tender mercies of HHS. What is the answer?

Mr. **Strauss**. Of course, the Alzheimer's victim moves through various levels of needed care. I will tell you about a client, a young woman, who wrote extensively about her mother who is 54, and testified in Washington at the last hearing.

My client recently bought an apartment for her mother. I helped the family to do it. This woman is being maintained in a safe, small environment. We have talked about the concept of finding one or two other Alzheimer's victims whom we could move into that apartment and have two or three families contribute to the cost of the custodial and skilled nursing care needed to maintain three victims. They would have to be at similar levels of development of the disease; they would have to be temperamentally compatible, so there would not be additional anxiety created; but I see a system of that nature being developed.

How to fund it? Well, I think that there ought to be some more coverage under medicare for this. I think that has to be a long-range answer. Perhaps again, means-tested.

Reasonable people can differ on that. We also ought to begin to look at finding some type of a private insurance system. You cannot buy a policy even when you are younger. Perhaps there ought to be a mandatory part C, where people are required to make additional contributions over and above their social security contribution to provide sufficient funding for long-term custodial care.

If you do not want to go that far, perhaps create an insurance policy, partially subsidized, as a rider to major medical policies, which would cover custodial care. I would buy it today, knowing what I know. I think it could be sold. I think that even if it needed some kind of subsidy, that might be something that the medicare program could look into, as an alternative, if you are not ready to go to the total assumption of this massive cost. And, as I said, I think the small type of living facility is something that should be explored. But that is a little beyond my expertise.

Chairman **Heinz**. Any other comments?

Ms. **Morscheck**. Yes, you may know in Pennsylvania there is concern about preassessment of individuals who appear at first sight to need nursing home placement. What is disturbing to those of us who work with the families and any others who have chronic, debilitating diseases is that this is being set up to save medical assistance money within the State, to essentially keep folks out of the nursing homes unnecessarily.

That is good, to keep them out, unnecessarily, but if the door is closed to individuals going to a nursing home and no funds are provided for comparable services in the community, such as assisting boarding homes; a boarding home that I went to, beginning to specialize in Alzheimer's patients in Pennsylvania, is charging about $1,000 per month, to allow this home to beef up their staff, to have full nighttime staff for wandering patients, and provide more stimulation during the day and more oversight of the individuals. That is far, far less expensive than those individuals might be paying, or costing the State, if they went in a nursing home facility.

This ought to be a sharing of, and not cutting of access to the nursing home, without making sure that there is some access to alternative programs.

I am not sure that it would double the cost of boarding home care if the Federal Government were involved in oversight; it might. Knowing what has happened with nursing homes, I think we could try to work against having that occur in the boarding home situation.

Chairman HEINZ. I commend you on your optimism. I hope you are right. All of my experience, I am more pessimistic perhaps than you are.

Ms. MORSCHECK. I think channeling experiments that have been going on ought to be giving us information about making available just a certain block amount of money for someone with a disability, and caring for them regardless of the setting. We ought to be getting feedback on how feasible that is.

Chairman HEINZ. I want to thank all three of you for making an outstanding contribution to this area. I thank you again for coming so far, Mrs. French, with so much on your mind. I thank Peter Strauss for his quite appropriate challenge to the committee. I thank Peggy Morscheck, in particular, for alerting people. I am sure there are many in the audience and presumably many hundreds of thousands more who will learn of what is being done, not just in Philadelphia, but in the 85 communities you mentioned. Many more communities remain to be organized and develop the kinds of self-help that you are bringing about.

We thank each of you. We are deeply indebted to you all.

We reached across the country in the last panel, from the Commonwealth of Pennsylvania to New York City and California. Now we get to talk to our hosts.

Ethel Mitty is a registered nurse, and Dr. Libow is the chief of medical services here. I suspect this group, in the audience, needs absolutely no introduction, of you to them, but I want to thank you for being here. Ms. Mitty, you will be our first witness.

STATEMENT OF ETHEL L. MITTY, R.N., DIRECTOR OF NURSING, CENTRAL HOUSE, JEWISH HOME AND HOSPITAL FOR AGED, NEW YORK, N.Y.

Ms. MITTY. Thank you. I am director of nursing at the Jewish Home and responsible for the patient care and educational programs of 120 nurses, 240 nursing assistants, serving 550 patients, many of whom have Alzheimer's disease or related dementia.

Statistics and facts alone do not tell the whole story about the disease. Nobody knows this better than nurses who are there with the patient and the families 24 hours a day.

Every patient admitted is evaluated with a view toward restoring and preserving their maximum level of function and personal integrity. The patients can be classed as minimal to moderately impaired, and moderately to severely impaired.

A moderately to severely Alzheimer's patient is someone who is forgetful, lost control of his bladder, cannot dress himself, needs help in cutting food, or completing his meal.

We do not use catheters to keep the bed dry or linen use down. We try to restore bladder control and regularity. The Alzheimer's patient who still has the ability to walk will be walked from place to place by a nursing staff. We will not tie this patient into a wheelchair and warehouse him for the rest of his life. The Alzheimer's patient who is immobile or rigid will receive passive exercise several times daily.

The moderately impaired Alzheimer's patient requires an approximate 3½ hours of direct nursing care in an 8-hour day. If the patient is not ambulatory, has to be tube fed, which 17 of our current population are, he would require 4⅔ hours of care in an 8-hour day. When you combine the hours of care needed and provided during the two 8-hour nursing shifts, the Alzheimer's patient requires at least 6 to 8 hours of care in a 24-hour period.

The problem is that long-term care institutions are only authorized and reimbursed to provide 4 hours, a maximum of 4 hours of nursing care during the 24-hour period. What the Government wants, and the families want, and the nurses want, cannot be done with current reimbursement levels.

Further, I do not believe that the DRG captures the range of needs and services of the Alzheimer's patients. I predict that the Alzheimer's patient will get even less care than heretofore before in the acute care hospitals.

The functional services which long-term care nursing provides are not simply or only custodial. The hands-on direct care does not include time spent in weekly multidisciplinary team conferences, and meetings with primary physicians, dietitians, a psychiatrist, social workers, activity workers, family meetings with the supervisor, and rehabilitation specialists.

It does not include time spent looking for lost clothing and lost dentures, and fights between patients. It does not include the time we need for inservice education, and by no means includes the time we need to document and assess nursing care.

Nursing in long-term care institutions is extremely demanding work. Nurses do not batter down doors to work here. Graduate nurses do not seek us out, and that is not necessarily the nurse I want.

We have very high standards for the nurses who work here. We expect the nurse to know and assess the effect of their ministrations, as well as other disciplines.

We want Sally Ride nurses but pay them Florence Nightingale wages. I expect, in truth, to get more than I pay for.

The nurse assistant in long-term care is the hands, eyes, and ears of the nursing home. We expect this person to be a more perfect human being, more loving and gentle than the rest. The strength of the nursing home is that we have nursing assistants who are gentle, patient, and caring, while confronting the most catastrophic effects of aging.

Inservice education and supervision are at the heart of the outstanding nursing home. Within the past 12 months, the nurses on all three tours have been trained or updated in physical assessment skills and psychotropic medication. Nursing assistants on all three tours have been educated in regard to major diseases and disabilities of the aging. The assistants have been trained in accident prevention, depression, dementia, and sensitivity. This fall, we will begin a seminar in the cross-cultural aspects of aging.

We are a clinical campus for nursing students.

But the time spent here by each respective group is unconscionably brief.

An issue that requires attention and appropriate action, particularly relating to Alzheimer's patients, is legislation to protect the patient from abuse, neglect, or mistreatment. The long-term care nursing sector has long demanded that the legislation which currently applies to nursing homes be applied to the hospital sector. The debilitated state in which the hospitalized elderly patient returns to his nursing home is outrageous; skin breakdown, no longer ambulatory, confused, incontinent. This is patient neglect.

It is no more difficult to demonstrate the outcome of remotivation therapy or sensory stimulation than it is to demonstrate the effect of bladder retraining. Both modalities cost money. We are forced all too often to choose.

We have restored significant function, mental and physical, for many of our Alzheimer's patients. In some cases, the confusion we saw was actually depression.

When we admit an Alzheimer's patient, the family is admitted also. We minister to the total needs of the patient and family. We do not apply physical restraints because we are lazy; we apply them because of a reasoned decision by the health team that it is too risky to let the patient walk unassisted. The family is a part of this decisionmaking and planning. You can purchase this judgment, reasoning, and planning, but at the present time we have the resources and capability to treat only a limited number of Alzheimer's patients.

Nursing homes have been castigated for many things. Of late, for refusing to admit the demented patient, the Alzheimer's patient. It is the irresponsible nursing home which admit an Alzheimer's patient but lacks the resources to care for him and his family. If I refused to admit an Alzheimer's patient, it would be because I could not safely and competently provide the plan of care and restoration needed.

I close with several recommendations: One, that the reimbursement formula get a jolt of reality. You will not get the kind, level, and quality of care required unless you provide the resources, protocols, and people to oversee this care.

I would also recommend that the regulations, surveys, and standards which currently apply to the nursing homes be applied to the hospital sector also.

Senator **Pressler** [presiding]. Thank you very much. The registered nurses and nurses really do the work. I have two sisters who are R.N.'s, registered nurses, and I am well aware of the wages of nurses.

I think your quote of your looking for Sally Ride quality for Florence Nightingale wages is a classic. I am aware of that. I have some questions, but they can wait until Dr. Libow makes his statement.

[The prepared statement of Ms. Mitty follows:]

Prepared Statement of Ethel L. Mitty

Thank you. I am privileged to speak before this Senate committee to describe and discuss some aspects of nursing care of patients with Alzheimer's disease, the challenges as well as the heartbreaks, the impact of this care on the patient and family—and on the nursing profession. I hope my testimony will increase the committee members' understanding of what is involved in treating Alzheimer's patients and, along with all the other testimony, stimulate ideas and legislative proposals that will result in better care.

Facts and statistics alone can never tell the whole story about Alzheimer's. And nobody knows this better than nurses who are there with the patient 24 hours a day. Nobody sees more clearly the impact on the patients themselves, who are terrified by the prospect of losing their memories, being unable to recognize those closest to them, being unable to care for themselves, having to be institutionalized—helpless and incompetent—for the rest of their lives. And nobody sees more clearly the toll taken by Alzheimer's on the patients' families, the mental as well as physical toll, the burdens they must assume, all the while forced to watch, much too often, the mental deterioration of their loved ones.

As director of nursing at Central House of the Jewish Home and Hospital for Aged, I am responsible for the patient care and educational programs involving 120 nurses and 240 nursing assistants who serve our 514 patients, almost half of whom—250—have Alzheimer's disease. I am also responsible for supervising internships of nursing students.

Every patient admitted is evaluated with a view to restoring and then preserving their maximum level of function and personal integrity. Alzheimer's patients can be classified as minimum to moderately impaired and moderately to severely impaired. The first classification, minimum to moderately impaired, is for that patient who can function somewhat independently, such as the patient who has lost control of his bladder, is forgetful, and needs help cutting food or completing a meal. This person may be ambulatory but his ambulation is aimless and frequently dangerous. The second classification, moderately to severly impaired, describes the patient who is totally helpless and unable to express need or discomfort. This patient might require feeding through a nasogastric tube, a tube that passes from the nose into the stomach. The nutritionally adequate feedings which are administered every 4 hours through this tube can only be done by a licensed nurse.

Both determining and in providing the activities of daily living or ADL, we are also involved in a social interchange between the nurse and the patient. This dialog is structured to include sentences of reality orientation. We attempt to stimulate questions from the patient that help him react to and be aware of his surroundings.

We do not use catheters to control incontinence or keep the bed dry; we try to restore bladder and bowel control or regularity and, failing that, we rigorously provide personal hygiene care. The Alzheimer's patient who still has the ability to walk will be walked from place to place by a nursing staff person; we will not place this patient in a wheelchair for the rest of his life. The Alzheimer's patient who is immobile or rigid will receive passive exercise several times daily, so that his limbs will not become contracted. We do not warehouse our Alzheimer's patients!

The moderately impaired Alzheimer's patient requires approximately 3½ hours of direct nursing care in an 8-hour day. If the patient is nonambulatory and has a nasogastric tube, which 17 of our current patient population have, he will require 281 minutes or 4⅔ hours of care in an 8-hour day. When you combine the hours of care needed and provided during the two other 8-hour nursing shifts, the Alzheimer's patient requires 6 to 8 hours of care, at least, in a 24-hour period.

The problem with all of this is that long-term care institutions are only authorized and reimbursed to provide 4 hours of nursing care during a 24-hour period for the Alzheimer's patient.

In other words, the long-term care Alzheimer's patients require more care than is recognized by the State or Federal Government. The government wants, and the families want, and the nurses want, what cannot be done with current reimbursement levels and formulas. Furthermore, I do not believe that the diagnostic related group variables capture the range of need and services for the Alzheimer's patient. I predict that the Alzheimer's patient will, sadly and unfortunately, get even less care than before in the acute care hospitals.

Just so that there is no misunderstanding, the functional services which long-term care nursing provides are not simple or only custodial. The hands-on direct care and supervision do not include the time spent in weekly multidisciplinary team conferences, the at least daily meeting with the primary physician, the monthly meeting with the dietitian to review weight and appetite, the monthly meeting with the psychiatrist to review medication, the at least twice weekly meeting with the social worker, the at least once weekly meeting or conversation with the family, several daily meetings with supervisor, the once or twice weekly meeting with the rehabilitation specialist, the hunt for lost clothing not to mention dentures, weekly inservice education, and last, but by no means least, the time to document the nursing assessment of the effect of the medications, treatments, nursing modalities, and care.

Quality assurance is not simply a game of paper compliance. The nursing profession has long held a commitment to standards and process; we do not need it imposed from without. The educated, trained, and supervised nurse in long-term care is not a mythological figure.

Nursing care in a long-term care institution is extremely demanding work. The nurse who thinks that work in a nursing home is not as hard as hospital nursing is simply fooling herself. The new graduate nurse does not seek us out; this is not necessarily the nurse I want, in any event. We do not have the staff or the time to teach the skills necessary to be a long-term care nurse. Nurses do not batter down the doors to work in nursing homes. They know of our high expectations and standards. We will not tolerate errors of lazy thinking and lethargy, nor accept shortcuts and irremedial shortcomings. The nurse who could hide her inadequacies in the hospital will not be able to do that here. We expect the nurse to know the desired effect of the medication administered and to assess the effect of their ministrations and those of the other disciplines. We want Sally Ride nurses but pay them Florence Nightingale wages. I expect, in truth, to get more than I am paying for.

The nurse assistant employed in a long-term care institution works for the same reasons that people seek employment anywhere: economics, interest, and job security. The nurse assistant in long-term care, however, is the hands, eyes, and ears of the nursing home. We should not expect him or her to be a more perfect human being, more loving, more gentle than the rest of us. And yet, the miracle of the nursing home is that we have nursing assistants who are gentle, loving, and caring, all the while confronted with daily crises and the most catastrophic effects of aging. Growing older and dying are more easily dealt with in the abstract. Facing and coping with death, old age, and sickness calls for the most fundamental strengths in a human being. We give our nursing assistance strength by giving them support—and knowledge.

Inservice education and supervision are at the heart of the outstanding nursing home. Information, education, performance evaluation, and audit are ongoing, as they must be. In line with our commitment and our needs, our inservice education program is intensive and around the clock. Within the past 12 months, our nurses have been trained or updated in physical assessment skills, psychotropic medication, nasogastric tube insertion, depression, and CPR. The nursing assistants have been educated in regard to the major diseases and disabilities of the aging; this included anatomy and physiology, medication, signs and symptoms, and nursing interventions. They have also been trained in obstructed airway emergencies, taking blood pressures, accident prevention, depression, and sensitivity. Next month, an anthropologist will begin a 10-session seminar in the cross-cultural aspects of aging; this program is for the nurses and nursing assistants.

We not only educate our own staff, but also serve as a clinical campus for nursing students from the three levels of nursing education. The time spent here by each respective group is unconscionably brief. Given the current status of government support for nurse education—and this is another serious problem which must be addressed—we must be thankful that the student has at least this contact. Both medical and nursing education have been remiss in educating the practitioners for gerontology. Five years from now we may not have a nursing shortage, but we will certainly have a shortage of nurses interested or equipped to work in long-term care let alone with Alzheimer's patients.

Still another issue that requires attention and appropriate action, particularly relating to Alzheimer's patients, is legislation to protect the patient from abuse, mistreatment, or neglect. The long-term care nursing sector has repeatedly asked that the legislation which applies to the nursing home be applied to the acute care hospital. The debilitated state in which the hospitalized elderly patient returns to his nursing home is outrageous: skin breakdown, no longer ambulatory, confused, incontinent. This is patient neglect. The moderately confused Alzheimer's patient has been severely compromised; those severely impaired are frequently beyond restoration.

Research in the medical, nursing, and social sciences clearly demonstrates certain programs that are effective for the Alzheimer's patient. Care of the Alzheimer's patient, I mean really care and caring, cannot be solely in the domain of the financial gymnast. It is no more difficult to demonstrate the outcome of remotivation therapy or sensory stimulation than it is to demonstrate the effect of bladder retraining. The former is seen in behaviors, the latter in the number of diapers used. Both modalities cost money. We are forced to choose all too often between the diaper—and the dressing retraining exercise. We need resources for both.

We have restored significant function, mental and physical, for many of our Alzheimer's patients. In some cases, the confusion we saw was actually depression. It is not just nurses who get burnt out; older people get burnt out, too. Alzheimer's patients get burnt out.

At the outset of my presentation, I mentioned the impact of Alzheimer's on the family. When we admit an Alzheimer's patient to the nursing home, the family is admitted also. We minister to the total needs of the identified patient and of the family. The hospitalized Alzheimer's patient with a fractured hip is "the 79-year-old demented patient with a fractured hip." Here, at the Jewish Home, the patient is known in his totality.

We do not apply physical restraints because we are lazy; we apply them because of a reasoned decision by the health team that it is too risky to let the patient walk unassisted. The family is a part of this decisionmaking and planning. You can purchase this judgment, reasoning, and planning, but at the present time we have the resources and capability to treat only a limited number of Alzheimer's patients.

Nursing homes have been castigated for many things. Of late, for refusing to admit the demented patient, the Alzheimer's patient. It is the irresponsible nursing home which admits an Alzheimer's patient but lacks the resources to care for him—and his family. If I refused to admit an Alzheimer's patient it would be because I could not safely and competently provide the plan of care and restoration needed.

I have attempted, in this brief testimony, to touch on a number of issues—some legislative, some professional, some emotional—effecting treatment of the Alzheimer's patient from the nursing perspective. It all comes down to commitment, resources, and recognition.

We now have the commitment, but lack the resources and the recognition. Nursing, in concert with other members of the health team, has the skills and accountability to care for the Alzheimer's patient. As legislators responsible to the public, you will never get the kind, level, and quality of care required and which you have every right to expect, unless you provide the resources, the needed protocols, and the qualified people to oversee this care.

Our society must improve its capability to treat the Alzheimer's patient. We cannot afford to undervalue the role of nurses in long-term care institutions. The consequences are too painful and too costly for all involved. Nursing is not ignorant of standards. Long-term care nursing has long struggled with standards of ignorance. The prospects for nursing are, I believe, inextricably bound with the prospects for the Alzheimer's patient.

Thank you.

STATEMENT OF LESLIE S. LIBOW, M.D., CHIEF OF MEDICAL SERVICES, JEWISH HOME AND HOSPITAL FOR AGED, NEW YORK, N.Y.

Dr. Libow. Thank you very much. Ladies and gentlemen, I admire the decision of this committee to focus the hearing on Alzheimer's disease and to hold the hearing at a nursing home, the place of residence of three-quarters of a million Alzheimer's patients on any given day.

As a geriatrician who has spent his career finding alternatives to nursing care, I underline the danger of the false promise of alternatives to nursing home care. It is my view that very few Alzheimer's patients have an alternative.

I urge the committee to think seriously about directing money to improve the nursing home rather than have us continue, as we do in this country, to look away from the home in the false promise that there is an alternative.

You have selected probably the most educationally committed nursing home in the United States. This strong commitment is based on our belief at the Jewish Home and Hospital that education is the only mechanism by which to achieve quality assurance.

We have developed a wide variety of educational programs for patient, family, and professional staff. For example, within several weeks of these hearings, all 132 senior medical students at Mount Sinai School of Medicine will experience a first in this country, an obligatory 2-week rotation into a nursing home, guided by our geriatric medical facility, in collaboration with the geriatric team of nurses, social workers, rehabilitation specialists, and others.

The rotation of these students will help them learn about the strengths and limitations of the frail elderly, their families, and, in particular, those with Alzheimer's disease. This is a far cry from the education of most physicians.

Indeed, Alzheimer's disease is without doubt, as pointed out so eloquently by the previous speakers, the single major illness of our era, affecting 4 to 8 percent of those over 65, but 20 percent of all those over the age of 80.

Alzheimer's is a disease, not a natural accompaniment of aging. Alzheimer's ranks, in my view, with the leukemias and the cancers as a great debilitating illness for patient and family. However, Alzheimer's differs from these malignant illnesses in four ways: First, the patient continues to live for many years; second, the cost of the illness is unmanageable by patient and family; third, the patient is threatened with loss of individual rights and liberties; and fourth, the patient seems to be a total stranger at times to family and friends. A case history may be helpful.

An 81-year-old former seamstress, widowed, mother of three adult children, a proud, self-sufficient individual, develops Alzheimer's disease. She lives alone in an apartment, unable to deal with financial and social obligations. She wanders the streets and has become very suspicious and paranoid about neighbors and family. She sleeps during the day, is incontinent of urine, cries frequently. Two of her adult children urge nursing home placement, a third disagrees and says her mother would never want that.

We do not know what mother would have wanted if she had been able to express her feelings at a time of mental clarity. A struggle occurs within the family. It is unclear as to what the right action is. The family physician prescribes medications which diminish sleeplessness, diminish paranoia, and diminish incontinence.

After a period of time, the patient is placed in a nursing home. Fortunately, that nursing home has a special unit for Alzheimer's patients.

Medical investigation reveals that the patient has a treatable thyroid disorder independent of the Alzheimer's. After 3 months of treatment the patient returns to her apartment, and is now at the apartment with a likelihood of living 5 to 10 more years, and probably being inhumanely placed permanently in a nursing home. What are the lessons from such a story?

First, Alzheimer's is somewhat treatable. A hopeless attitude is inappropriate.

Second, improved education of physicians, nurses, social workers, and the public is necessary.

Third, a "penultimate will" is essential in order for all of us to maintain some control of our lives, even in the face of Alzheimer's disease. Everyone, while still healthy and mentally clear, should express in a legal document, our wishes, philosophies, and choice of surrogate in the painful eventuality that we should develop Alzheimer's disease. I have called this document in previous publications, a penultimate will. It is a legal instrument in New York and California, and is now about to become a legal instrument in Florida and Michigan.

Fourth, teams of clinicians are necessary at each community to assist the family, patient, and physician in dealing with the Alzheimer's patient. In fact, such teams do exist in certain communities now, but all too few in this country.

Fifth, excellent nursing homes must be highlighted in each community so that proper placement without guilt and excessive pain may occur.

Sixth, we will ultimately prevent and/or cure Alzheimer's. I am confident of that. In the meantime, we must focus not only on cost effectiveness, but also on human effectiveness, for these patients and families.

Thank you.

[The prepared statement of Dr. Libow follows:]

PREPARED STATEMENT OF DR. LESLIE S. LIBOW

Mr. Chairman and members of the committee, I admire your decision to focus these hearings on Alzheimer's disease and to hold the hearings at a nursing home, and am pleased to have this opportunity to testify. Indeed, you have selected what is probably the most educationally committed nursing home in the United States. We, at the Jewish Home and Hospital for Aged believe that education of professional staff, families, and patients is the only mechanism to quality assurance. For example, within weeks of these hearings, all 132 senior medical students at the Mount Sinai Medical School (MSMS) will experience a first in this country. These students will spend 2 consecutive weeks at the Jewish Home and Hospital for Aged [JHHA] guided by a select group of faculty and fellows in geriatrics, where they will learn from firsthand experience about the frail elderly, about the clinical and ethical decisions which are unique to this population, about the differences between hospitals and nursing homes, and most importantly, about Alzheimer's disease, the major disease leading to placement of patients in nursing homes. For every Alzheimer's disease patient in a nursing home, there is at least one or two still residing in the community. To this extent, our joint JHHA and MSMS effort is developing outpatient services for the community residing elderly with Alzheimer's disease and for their families, in an effort to reduce cost to society and to improve the quality of life. But for those who cannot remain at home (33 to 50 percent of all Alzheimer's patients), it is fortunate that excellent nursing homes do exist.

Alzheimer's disease is, without doubt, the single major illness of our era and certainly of the forthcoming century. It affects about 4 to 8 percent of those over 65, and about 20 percent of those over 80. It is a disease, not a natural accompaniment of aging as, for example, graying of the hair. It ranks, in my view, with the leukemias and the cancers as a great debilitating illness for patient and family. It differs from those malignant illnesses in three ways: (1) The patient continues to live for many, many years after the onset; (2) the cost of the illness is unmanageable by most individuals; and (3) the patient is threatened with a loss of the individual rights and liberties which are his due. Thus, the families of Alzheimer's patients are faced with an unusual and sad situation. They are challenged to assist a patient whose illness is difficult to treat, whose social and financial burdens involve them in a variety of ways, whose life will extend for years, and who often is no longer the same person that they have known during their lifetime—at times, a total stranger.

CASE HISTORY

A brief case history will highlight the problems in care. A 78-year-old engineer residing in New York City, father of three adult children, grandfather of seven, devoted and loving husband, effective community leader, develops Alzheimer's disease. Over a 10 month period, he is unable to function socially, making serious banking and bill-paying errors, failing, at times, to recognize family and friends, and becoming intermittently incontinent of urine. His children live at some distance from his home; in New York State, Washington, D.C., and California. His wife now has the responsibility of running their household, arranging for his health care, and dealing with their increasing isolation. She states that their friends continued to come to their home to play bridge, and for other events, for a brief period, but soon did not know how to talk with her husband or her. The patient recognizes and talks coherently and appropriately with his wife on only rare occasions. Most of the time he doesn't seem to know her. He is sexually demanding and, at times, believes that his wife is unfaithful to him. His reasoning, orientation to time and place, memory for recent and distant events is impaired, his intellect and judgment have badly deteriorated and he is, in addition, depressed and cries frequently. He sleeps during the day and is awake most of the night. He wanders out onto the street and is unable to find his way home. Two of his children strongly urge their mother to place him in a nursing home. A third child strongly disagrees with such placement. She says that he would never want this, and she "couldn't do this to him" after 55 years of marriage. She, herself, is now becoming ill, unable to sleep, and suffering from weight loss, loneliness, anger, and depression. It is the memory of the 55 happy years that "keep her going."

At times he is physically threatening to her, with bursts of violence that never occurred during their 55 years together. His physician has prescribed medications for sleep and for his excessive suspiciousness, wandering, and depression. He began the treatment for the global mental dysfunction with the newest of unproven though hopeful remedies which contain cholene, a chemical component of vital brain neurotransmitters. The wife and children engage in a painful family struggle about nursing home placement. The patient's wandering sleeplessness and assaultive behaviors diminish somewhat with the new medications. It is likely that the patient will endure another 5 to 10 years, ultimately being placed in a nursing home for continued care.

PATIENT CARE HIGHLIGHTS FROM THE CASE HISTORY

Five additional "care" points are highlighted by this touching and very real case: (1) When an older man develops Alzheimer's disease he is likely to have a spouse who can assist him. Though Alzheimer's disease affects both sexes it is much more prevalent among women. Since elderly women usually outlive their husbands, they are very likely to be alone when Alzheimer's disease strikes and, thus, frequently turn to nursing homes for surrogate support. We need to create less expensive, community-based surrogate support. This is not a likely achievement without prior planning. In the meantime, perhaps for the next 10 to 20 years, we must come to see the nursing home as a necessary part of the life cycle for many, reflecting the natural social changes of a graying Nation; the physician should, where appropriate, support the concept of nursing home placement through diminishing family guilt and tension. (2) Friends and, at times, family disengage with both patient and spouse, partly because of not knowing how to approach or talk to the patient, and partly because of the fear that this illness induces. We must quickly and clearly educate both public and professionals to the approaches to Alzheimer's disease. This education effort should be lead by medical centers and, most particularly, by nursing homes. (3) Patients with Alzheimer's disease have more residual mental competence than meets the awareness of laymen or professionals. It is likely that many can decide about some key life decisions remaining; for example, decisions about inheritance, placement in nursing home, etc.

THE PENULTIMATE WILL—A MECHANISM TO INSURE SOME CONTROL OVER ONE'S LIFE

I recommend the penultimate will as a legal instrument which will allow every person critical control over their remaining years, should Alzheimer's disease befall them. In this will, written at any age, but at a time of mental competence, we address the possibility of ensuing mental impairment and remaining years of life, select our surrogate, and state our desires and philosophies. Such an instrument greatly aids the clinician, the court, and most of all, the patient as is clear in the case described today. Clinical care of the Alzheimer's patient is not a one clinician/

one patient determination. It involves several clinicians (physician, social worker, nurse, etc., patient and family). As at the JHHA, teams of providers are molded into an instrument of care available to clinician, patient, and family. Every community must quickly develop a geriatrician leader who, in turn, will mold the team. Treatments are available. As seen in our case, there are treatments and maneuvers for the sleeplessness, the paranoia and painful ideas of suspicion, and the depression. In addition, there are team supports and approaches for the newly available "time without direction," and for the financial, legal, and ethical issues.

To improve the care of Alzheimer's patients, we need to:

(1) Increasingly educate all laymen and health providers about the illness.

(2) Develop teams in each community; in particular, train special physicians, called geriatricians, to lead these educational efforts. This, in effect, is well underway with the JHHA/MSSM newly established program in geriatrics.

(3) Have the physician take an active, therapeutic role with patient and family, including guidance as to prognoses, placement, etc.

(4) Have the entire populace complete a one page penultimate will to provide safe protection and safe direction in the event of Alzheimer's disease; and

(5) Support increased research into this disease, a matter which Dr. Butler has played a major role, and which he will address today.

I am convinced that in the near future we can conquer and prevent Alzheimer's disease. We can certainly now do much more than is being done to improve the care of the patient and to assist the family.

Thank you.

Senator PRESSLER. I think you both have presented excellent testimony. May I ask, how many beds does this home have?

Ms. MITTY. It has 514. There is a Bronx division as well.

Senator PRESSLER. So you would consider this, your total about 1,100 beds?

Ms. MITTY. Yes.

Senator PRESSLER. How many are Alzheimer's patients?

Ms. MITTY. I would think 50 percent are.

Senator PRESSLER. Fifty percent. How many of those are under, roughly, 70 years of age? Do you have any way of knowing?

Ms. MITTY. Did you say 65?

Senator PRESSLER. How many are under 70?

Ms. MITTY. Very few.

Senator PRESSLER. If a link could be found to treat or cure Alzheimer's, then this institution, 50 percent of its patients, depending on what may occur later in some other form, 50 percent of the patients in this institution would be affected; correct?

Ms. MITTY. Yes.

Senator PRESSLER. I think that is a very significant number. As I mentioned earlier, the nursing homes that I deal with on a regular basis are much smaller. Costs in some cases are higher because of that lower volume. We have many of the same problems that you have.

So, I think that, although we are from States that are far apart, I am here to learn some things, but I am finding some of the same type of testimony I heard in the South Dakota hearing a couple of weeks ago.

You mentioned that you have a difficult time in getting nurses to work in this specialty. At least they are not trained in this area, or perhaps there are other more attractive things. What is the reason for that?

Ms. MITTY. I would say, in part, it is a psychological reason for not wanting to work in a nursing home; it is not as exciting as hospitals, or so it would appear to the persons there.

I think that a nurse's education and training have not been instilled enough for them to be thinking about the long-term care sector. There is not even that germ of interest.

I think for anyone to work in long-term care, any professional, the rewards are hard to see. The goals are hard to achieve. So that the nice feeling that you would get from being a helping person are sometimes hard to grasp.

Self-esteem rewards that we need at work are sometimes difficult to capture in a long-term care setting.

Senator **Pressler**. I think you mentioned something that is a great problem. I have heard that the 4-H Clubs of America have a project of young people visiting nursing homes with the approval of the homes, of course, but we do not look upon work in a nursing home as exciting as work in a hospital.

It is a difficult place to work, although it is rewarding. There is a problem of attracting personnel needed with the increasing aging population coming. I have been one who has urged that gerontological studies and learning centers make us more aware of the aging process. It is important, that this not be an unattractive thing.

Indeed, I think that businesses, commercial institutions, and television ads have a responsibility in this area.

The aging process is not considered an attractive process in our society, the perception of that, perhaps, has led to spinoff problems, in terms of getting the best or most dedicated people. We need to reeducate ourselves about the work that is done in the nursing homes. I think you have made a good point this morning.

I shall yield to my colleague.

Chairman **Heinz** [resuming chair]. Mr. Acting Chairman, you are doing a superb job. You may continue.

Senator **Pressler**. That is about all of my questions.

Chairman **Heinz**. I want to apologize to Ms. Mitty and Dr. Libow for missing your testimony. I had to be out of the room for a moment. I managed to read your testimony. I have yet to get to yours, Dr. Libow.

On reading your testimony, though, there were two things that struck me. The statement that, your concern about the debilitating state in which the hospitalized elderly patient returns to his nursing home is outrageous. What is the problem? Is this something that should be best left to the medical profession to come to grips with? We like to think, when we turn a patient over to a nurse or doctor, it is not going to be hazardous to their health.

I do not want to create a terrible rift between you and the medical staff in asking the question.

Ms. **Mitty**. Dr. Libow and I go back a long way. I think the problem with elderly people, Alzheimer's patients in a hospital, is really two-thirds a nursing issue and one-third a medical one.

I do not think the nurses we are turning out from our educational system know how to give fundamental nursing care. I think that is showing up, not just back in the nursing home, but showing up all over.

I think we have a problem with the accountability system, or the way we see our patients. No one is minding the store. There are problems we are seeing with the elderly.

Chairman HEINZ. Can I interrupt you to ask what is missing from nursing education?

Ms. MITTY. Patient contact. One of my recommendations in the testimony is that I supported, and that I need, an empty school-of-nursing building to house my nursing staff.

We are not training nurses with hands-on skills and intellectual skills really to do the job.

Chairman HEINZ. What you are saying is that when you get your R.N., somehow you manage to get it without really working with patients?

Ms. MITTY. Yes; you can get an R.N. without barely touching a patient. You can sit for the licensing exam. It is a different type of training than it was 15 or 20 years ago. I think we are all suffering from it.

Chairman HEINZ. What should we be doing about it?

Ms. MITTY. Well, I think that you should take a look at nursing education and put demands on the profession for performance or an outcome——

Chairman HEINZ. There have been from time to time some health manpower programs that do support nursing training, but they have never gotten into the curriculum kinds of issues. These issues have been left to individual States to determine.

Are you saying we should go into that?

Ms. MITTY. I think you are entitled to know what your money purchases, and to look at test scores, numbers of incidents of infection, of falls, of complications, secondary to the hospitalization. There are ways to look at the effect of what you are purchasing. I think that that can be within your domain as well.

Chairman HEINZ. We have traditionally looked at purchasing in terms of the ability of a student to attend an accredited school as opposed to the product, the product of that education. It has been more of an avenue to provide opportunity for the individual as opposed to a means to assure the quality of what is taught or produced.

I hear what you are saying.

Let me ask you this question, then: Of all of the things that you think we at the Federal level should do, and I ask this of both of you, what would be the one or two most important things you would like us, upon returning to Washington, later today, to do?

Dr. Libow, why not take a crack at that?

Nurse Mitty is composing a long list and slowly scratching them out.

Dr. LIBOW. The key to improving quality of care for those at all ages, particularly the elderly, is improved education of health care profession and emphasizing a different set of goals. Too little emphasis and too few dollars have been spent on that.

You cannot attract nurses, physicians, or social workers to a nursing home or to work in community agencies, with the elderly ill, unless we educate everyone toward new goals.

The goals of dramatic cure are not appropriate goals in dealing with 80-year-olds, with some exception. Relief from pneumonia is welcome at any age, but with the elderly, it is often a matter of a little less depression, a few less falls, a little less incontinence, and perhaps a little more time out of the nursing home. Those are the goals we need to imbue in students and health care professionals.

Chairman HEINZ. I commend you for that statement. I would like to enlarge on its implications based on a hearing we held some 2 months ago.

We held a joint hearing with the House Aging Committee on drug misuse and the elderly. The hearing was replete with testimony, through informed witnesses, some of them doctors. Many of them spoke of doctors prescribing and then overprescribing, prescribing more medication to take care of symptoms created by the incorrect use of another drug. Persons who might have gotten by just fine with aspirin or a small dose of heart medication ended up on some 15 drugs.

Each drug tried to combat the apparent symptoms of another drug without the physician knowing about it.

You seem to be saying that our medical profession, like the American society, is often accused of being oriented toward a quick fix. They are trained to do quick fixes. They are trained to deal with acute care issues.

In a sense, it is also part and parcel of our need for instant gratification.

So you are saying to medical schools, they do not fully understand the orientation that they are imbuing their graduates with. Is that a fair statement?

Dr. LIBOW. There is a mismatch between the educational system and the demography. That is it. We, at Mount Sinai, and we, in the Jewish Home and Hospital for Aged, we have changed that mismatched emphasis. Similar changes are happening in other places in the country, but there are 127 medical schools and a large number of nursing schools where little change has occurred.

You asked for other key changes to emphasize when you go back to Washington, D.C. There is something about the medical and hospital payment system which does not recognize the demography either.

The physician and hospital get paid for technology. Put in a scope and get well reimbursed for the great skill.

In contrast, you do not get paid for time and other skills that are reflected in obtaining a long history from a patient, in holding a patient's hand, or in making a house call.

If you change the payment system, Senator, you change the entire approach to the elderly in this country.

Chairman HEINZ. I am almost tempted to ask if we should go to a time and materials basis rather than a turnkey basis. How would you change it?

Dr. LIBOW. The changes are fairly straightforward, and I would be pleased to discuss them with you and the committee. The essence of the change, Senator, would be to come up with a formula that reflects dollars for time and dollars for critical nontechnological remedies and approvals.

Chairman HEINZ. What you necessarily are suggesting, then, is, and I wasn't being facetious, time and materials.

Dr. LIBOW. My answer is very simple. It is the heart of the issue; if you want to change the health system quickly and produce health care for the elderly, change the emphasis of reimbursement from technology to clinical care.

Chairman HEINZ. An interesting and provocative thought.

Any other comments?

Ms. MITTY. No; I would second what Dr. Libow said. Before you change the reimbursement system, please take a look at what you have.

Chairman HEINZ. Which change are you referring to? The reasonable cost system that we think we more or less have now, or DRG system?

Ms. MITTY. Referring to DRG, Federal health surveys, titles 18, 19, referring to systems that are in place and chewing up professional staff that could be doing other things. Before you implant something else, I think we need to look at what we have in-house.

Chairman HEINZ. Are you saying, so that I understand you, now at least say, in moving to DRG, let it have time to work itself out? Do not change it tomorrow?

Ms. MITTY. I am not convinced we should erase the DRG. We have not tested that yet. I know the Federal survey, as it currently operates, does not look at outcomes at all. It does not really look at health care delivery.

We are not really in a quality assurance mode. We really do not know if we are getting our dollar's worth.

I recommend before we go and spend dollars, either more or differently, you have to clean out or clean up what you have now.

Chairman HEINZ. Thank you. Do you have a short, 500-page paper on how to do that? We will contact you later for your thoughts on that, I am sure.

In your testimony, you said you wanted to clean up the present system. Let me discuss that issue with you later a little bit further.

Thank you both very much.

Our third and last panel includes Janet Sainer, commissioner of aging, New York City; it includes a dear friend of mine, former director of the National Institute of Aging, and now the chairman of the Department of Geriatrics and Adult Development, Mount Sinai Medical Center, Dr. Robert Butler; and the deputy director of Brookdale Center on Aging, Samuel Sadin.

Let me warn you that Mr. Strauss and I conversed in the corridor and we will have an additional task for you at the conclusion of your testimony.

STATEMENT OF JANET S. SAINER, COMMISSIONER, NEW YORK, N.Y., DEPARTMENT FOR THE AGING

Ms. SAINER. I want to express my appreciation, and that of Mayor Koch, for holding this hearing in New York City and giving me an opportunity to testify on a subject of such deep concern.

Indeed, because we are aware of the increasing incidence of Alzheimer's disease and its increasing significance, we are holding a mayoral conference on November 3, to give recognition to the serious impact of this disease. We hope that you, or members of your committee, can be with us on that day as we review some of the ways in which we in New York City can more effectively deliver services to Alzheimer's victims and their families, can sensitize health and human services providers to the complexity and enormity of this disease, as well as highlight key legislative and policy issues. The hearings you are conducting around the country bring Alzheimer's to the fore. For this, you are to be commended. We would hope that as a result there will be more progress and more action taken.

I would like to focus today on some of the community-based issues. We have heard from a number of institutional people, and that is a very important dimension of the whole problem. We have a great concern for community-based care and the increased need to take care of an estimated 50,000 noninstitutional persons living in New York City who are afflicted with Alzheimer's or similar disorders.

New York, like other urban areas throughout the country, has seen significant changes in its elderly population over the past 10 years. The 75- to 84-year-old cohort has risen 15 percent since 1970, while those 85 and over increased by 37 percent. In addition, the number of elderly living alone has increased in the past decade by over 13½ percent. Clearly, more and more of our aged are kinless and mateless, and they are the very old, very poor, and usually female.

Moreover, the lives of our urban elderly are different from those of their counterparts elsewhere. You know we have a large number of apartment dwellers, and many live in communities which have undergone enormous change in the past 10 years. They no longer have the doctors they used to have. There is nobody there to recognize some of the subtle behavior changes which signify the onset of Alzheimer's.

We know that we get calls at our office from the police, or neighbors, when they hear of somebody letting the tub flow over, or of forgetting to turn off the gas.

These kinds of calls are familiar ones. Not only social services providers and health professionals, but the police and landlords and those in housing projects, are beginning to wonder how to cope with the problems that victims of Alzheimer's disease present.

I want to underscore what Peter Strauss said about the issue of couples. The spousal issue is indeed a critical one. He made such an important point of it, I do not think I have to reemphasize it to you.

I also want to underscore Senator D'Amato's and your concerns in connection with increasing funds for research in Alzheimer's disease. I hope that that can be a very concrete result of the hearings that you are conducting. What I am particularly concerned about, however, is the little assistance that is available in the community when families are willing to care for their elders who are able to remain in that community.

Most of the services that do exist require an income eligibility. Chronically ill patients who require long-term care must spend down to medicaid eligibility levels. In New York City, we have one of the largest and most effective home attendant programs for medicaid eligible clients anywhere in the country. However the patient must be able to direct those who give the care, and the progressive deterioration of the patient prevents them from assuming such responsibility, unless there is family to provide this supervision.

Medicaid eligibility is currently $6,400 for a couple in New York State; assets cannot exceed $4,200, and $1,500 per person can be maintained for burial expenses.

At this time, only 17 percent of New York City's elderly are medicaid eligible. Therefore, when we try to address the problem of long-term care, putting sole emphasis on income eligibility, rather than level of disability is something that must be changed.

Having income above the medicaid eligibility level does not automatically insure one's ability to pay for needed care and services. Some of the people who testified earlier, Mrs. French particularly, highlighted that. Most recent data indicates that half of those 65 and over in New York City had incomes under $10,000.

I do not have to tell you about the high costs cited before for privately purchased assistance. What is important is that our current system pauperizes spouses, and overburdens adult children who assume responsibility for their disabled relatives.

We urge action. Our primary recommendation is that a continuum of social and medical care, including community-based inhome services, adult day care, respite, and quality institutions with trained staff, needs to be part of the medicare system. Unfortunately, medicare continues to be an insurance program to cover the costs of acute illness. We must acknowledge and act on the fact that the elderly who suffer from chronic illnesses need long-term care services.

Senator Heinz, we are pleased with the legislation you have introduced. But I say to you, frankly, that we have to look beyond the medicaid-income-eligible population, if what you are proposing is to be effective for the large number of elderly and their families in this city and across the Nation.

I urge you to consider the total cost this society pays through local, State, and Federal resources to provide medicaid and medicare funded services. If we look at what is currently paid through these systems, I think you will find that what we are proposing is not that much more costly.

In addition to Federal financing of the services required by Alzheimer's patients and families, there is no question that we want to increase support for research. We also support assistance through the income tax credit, which you had earlier mentioned was one of three bills being proposed.

Another issue we would like to underscore is that the Federal Government, while increasing incentives for community-based home care, must assure that there are an adequate number of nursing home beds to care for those who must be institutionalized.

Furthermore, the Federal Government should insure that nursing homes accept patients with Alzheimer's and related disorders. Too often, even if medicaid or private funds are available, the Alzheimer's patient is shunned by institutions because they feel unable to manage such patients.

The area that Ms. Mitty spoke of before, of being sure that the institutions can give quality care and yet having adequate beds and space in place for such patients, is something to which more attention must be given.

I would underscore the need for increased training of nursing home staff and home care aides who can care for people with Alzheimer's disease.

As the director of the area agency on aging here in New York City, I would like to touch on one other issue.

I would like you to include in the reauthorization of the Older Americans Act new program directions, as well as increased funding for programs that address the needs of those suffering from Alzheimer's disease and related disorders, and those who are chronically disabled. Area agencies could become the repository for information on all diagnostic and service programs for families and patients of Alzheimer's in their geographic areas.

The area agencies on aging should be, and could be, a first stop for those who need help and guidance. Perhaps this could be accomplished in collaboration with the local associations of ADRDA. ADRDA is to be commended for the efforts they are making in providing information, making referrals, and creating support groups. They need help and funding.

I think the area agencies would be more than willing to work collaboratively with these organizations. As we consider some of the critical informational needs that families have on reimbursement issues, legal services, and support groups, I think we have the capacity, with very few dollars, to be able to add that dimension of assistance through the Older Americans Act.

In conclusion, I would like to reemphasize that we need substantially more Federal funding to support research on the causes, treatment, and cures of Alzheimer's and related diseases. We need medicare to help finance long-term care, including home care for the chronically disabled. We need a coordinated long-term care system that insures a continuum of care, including in-home and community-based services.

We need an income tax credit or an allowance to assist families. We need to be assured that there are sufficient nursing home beds in each State adequate to care for the Alzheimer's patients, and ready to accept them. Finally, we need to strengthen the capacity of area agencies to assist patients and families of Alzheimer's and related disorders, to serve as a central resource center, to be a source of counseling and guidance, and to work collaboratively with those most closely affected.

It may be quite awhile before science finds answers that will lead to the cure or prevention of Alzheimer's. Meanwhile, by providing the vital day-to-day support needed, we can lessen the tragic impact of this most dreaded disease.

Then, perhaps, the title of today's hearing being "Endless Night, Endless Mourning: Living with Alzheimer's," can be translated to "Living With Alzheimer's More Effectively."

Chairman HEINZ. Thank you very much. A most comprehensive and extremely thoughtful statement.

[The prepared statement of Ms. Sainer follows:]

PREPARED STATEMENT OF JANET S. SAINER

I am Janet Sainer, commissioner of the New York City Department for the Aging, the area agency on aging which acts as an advocate on behalf of our more than 1.3 million elderly 60 years of age and older. Mayor Koch has asked me to thank you for holding this hearing in New York City, and giving us an opportunity to testify on a subject which is of deepest concern. Indeed, because we are aware that the incidence of Alzheimer's disease is increasing significantly, we in New York are taking a step to give recognition to its serious impact on the elderly and their families. Last spring, the mayor personally asked the department for the aging to convene a task force of city officials, major medical and social service leaders, and family caregivers, to plan a citywide Mayoral Conference on Alzheimer's Disease, slated for November 3, the beginning of National Alzheimer's Month. The goal of this conference will be to address the most effective ways to reorganize and deliver services to Alzheimer's victims and their families, to sensitize health and social service providers to the complexity and enormity of this disease, as well as highlight key legislative and policy issues. Moreover, to augment the efforts of this conference, a resource directory is being prepared which we hope will serve as a guide to what services are available and how best to gain access to them.

In holding our conference, we are responding to an increasing need among older people and those who care for them. Although there are no exact figures on the numbers of persons who suffer from Alzheimer's disease and similar disorders, recent reports in "Science" estimate that from 5 to 10 percent of those over 65, or as many as 2 million Americans are afflicted. Worse, as we conquer or ameliorate other illnesses which extend the lives of individuals and increase the number of elderly, the incidence of Alzheimer's disease rises. It is projected that the prevalence of these illnesses will more than triple in the next 50 years.

Up to now, those who were affected by Alzheimer's disease and those who care for them have tended to close themselves off to cope silently and with little help, except for institutions. Until very recently Alzheimer's disease has been viewed as an institutional rather than a community-based problem. Indeed, an estimated 50 to 60 percent of nursing home patients have some form of dementia.

Some simple arithmetic, however, would indicate that, by the most conservative estimates, at least a million Alzheimer's victims are maintained at home. In New York City alone there are probably upward of 50,000 persons over 65 living in the community who are afflicted with Alzheimer's or similar disorders.

I should like to add an urban perspective to these figures. New York City, like other urban areas throughout the country, has seen significant changes in its elderly population over the past 10 years: It has grown older and it has become increasingly live alone. The 75 to 84 year cohort rose 15 percent from 1970, while those 85 and over increased by 37 percent. In addition, the number of elderly living alone increased by 13.4 percent in the past decade. Clearly, more and more of our aged are kinless and mateless—they are the very old, the very poor, and usually female. Moreover, the lives of urban elderly are different from those of their counterparts elsewhere. They are apartment dwellers, and many live in communities which have undergone enormous change in the past 10 years. Their private doctors are growing older and are not being replaced by new physicians. Thus, there is often no doctor who knows them personally and who can recognize the subtle behavior changes that herald the onset of a deteriorating condition. The neighbors of elderly who live alone are often casual acquaintances, and younger who also may not be aware of changes in the older person until some overt act, such as turning on and forgetting the gas, or letting a tub overflow, occurs, which threatens not only the older person but his or her neighbors. Our department is only too familiar with calls from the landlords, neighbors, and the police, asking for help for such elderly.

As for elderly couples, the physical and emotional strain placed on the care-giving spouse is almost beyond belief. As difficult as it is for children to watch the changes in an older parent, how much more tragic it is for a spouse to see such deterioration.

Further, although families are available to most of our elderly, they, too, are apartment dwellers and usually do not have room to care for an older deteriorating parent.

We are well aware that a diagnosis of Alzheimer's disease changes the life of the entire family for as long as the patient lives. And recent studies indicate that most families maintain their relatives at home for 4 to 8 years after the diagnosis. Families are caught in the dilemma of increasing demands and decreasing resources. Progressive deterioration and unpredictability of symptoms force the patient and the family to adjust continually to new problems and higher levels of impairment.

Until we achieve a major breakthrough in research to prevent the onset of Alzheimer's disease and other related disorders, an urgent need exists to develop programs and services to assist families who can care for their stricken members and humane services for those who have no families.

At present, all too little assistance is available in the community. Moreover, most of the services that do exist, require income eligibility. Our current system forces our chronically ill aged who require long-term care onto medicaid. For example, in New York City, we do provide in-home services under medicaid. But to be eligible for home-care services, the patient must be able to direct and supervise the home attendant. The progressive deterioration of these patients prevents them from assuming such responsibilities. On the other hand, when there is family to provide this supervision, the family must generally "spend down" to medicaid eligibility which is $6,400 for a couple in New York State. The family must also spend all their assets down to $4,200, plus $1,500 per person for burial expenses.

At this time only about 17 percent of New York City's elderly are medicaid eligible. The large majority are not. However, lack of medicaid eligibility does not automatically insure one's ability to pay for needed services and care. Most recent income data for the city's elderly indicate that half of those 65 and over had incomes falling between $4,000 and $10,000. To privately purchase assistance costs approximately $5 an hour on a part-time basis. Families and individuals requiring full-time, around-the-clock help, get a bargain rate from $250 to $400 weekly. How many elderly or their families can support such costs?

Our current system pauperizes the caring spouse and overburdens adult children who assume responsibility for their disabled relatives.

We, therefore, urge as our primary recommendation, that a continuum of social and medical care—which includes community-based in-home services, adult day care and respite, and architecturally designed institutions with trained staff to take into account family and patient needs—be financed under medicare.

Medicare continues to be an insurance program to cover the costs of acute illness. We must acknowledge that the elderly suffer from chronic illnesses and need covered long-term care services. I recognize that this may be an inopportune time to suggest that medicare must cover more services when Congress is faced with shortfalls in the medicare trust funds. But I would urge you to consider the total cost this society pays through local, State, and Federal taxes to provide medicaid and medicare services. When you do not provide long-term care under medicare, you pay for increased lengths of stay in hospitals, or you send patients to more costly nursing homes who could be cared for at home. I suspect, and I admit I have no documentation, that the families caring for Alzheimer's patients experience higher incidence of physical and emotional illness. This too, adds to our national health care bill.

In addition to Federal financing of the services required by Alzheimer's patients and families, the Federal Government must increase its support both for basic research into the causes and cures of Alzheimer's and related disorders, and for demonstration programs directed to alternative living and service arrangements for patients who require custodial care and supervision of their person and property in order to be maintained at home as long as possible. For such persons, particularly if they can be housed in close proximity to each other, a grant to a single agency to care for a number of Alzheimer's victims, including supervision and training of home attendants, group shopping, and meal preparation for all clients might prove both cost-effective and humane. New York State's enriched housing program provides some of these services for the frail elderly. Might we not look at the applicability of the same concept to illnesses like Alzheimer's? In addition, Federal funds should be made available to renovate existing nursing homes to permit them to care for Alzheimer's patients.

When, however, families can and do assume the burden of care for elderly disabled relatives either by taking them into their homes or by paying their bills, we strongly support assistance to them through the mechanisms of income tax credit or an allowance in the case of lower income families who do not pay much in taxes and for whom the fiscal burden is greater.

The Federal Government, while increasing the incentives for community-based home care, must simultaneously insure that there are an adequate number of nursing home beds to care for those who must be institutionalized. Further, the Federal Government must insure that nursing homes accept patients with Alzheimer's and related disorders. Too often, even if medicaid or even private funds are available, the Alzheimer's and dementia patient is shunned by institutions who feel unable to manage such patients. In this regard, we would also like to see increased training of nursing home and home care staffs who care for Alzheimer's patients. An informal survey conducted by the department for the aging of some 60 nursing homes in New York City found only eight had specific training programs on Alzheimer's disease for staff and special care regimens for Alzheimer's victims. The majority of nursing homes are not adequately prepared for the complex task of providing quality care for an Alzheimer's victim.

As the director of an area agency on aging, I would also urge you to include in the reauthorization of the Older Americans Act new program directions, as well as increased funding for these programs. The area agencies should become the repository for information on all diagnostic and service programs for families and patients of Alzheimer's and related disorders for their geographic areas. It should be the "first stop" to direct people for help. The area agencies should also be funded to assist existing support groups, or provide seed moneys where no such groups exist. Families cannot cope alone with caring for these patients. They need strength and understanding from persons who are sharing the same burdens. The Older Americans Act legal services programs should be expanded to provide assistance with the legal problems families and agencies face with managing the affairs of Alzheimer's patients.

In conclusion, I would reemphasize that:

We need substantially more Federal funding to support research into the causes, treatment, and cures of Alzheimer's and related diseases.

We need medicare to finance long-term care, including home care for the chronically disabled.

We need a coordinated long-term care system that will insure a continuum of care which includes in-home and community-based services. And these community services should include alternate living and service arrangements, as well as respite and adult day care.

We need income tax credit or an allowance to assist families who care for relatives at home.

We need a Federal requirement that federally supported nursing homes accept dementia patients, and we need to insure that there are sufficient nursing home beds in each State in architecturally appropriate and adequately staffed institutions for patients with dementia and related diseases.

We need to increase the training of nursing and home-care staff who care for Alzheimer's disease patients.

Finally, we need to strengthen the role of area agencies to serve patients and families with Alzheimer's and related disorders when the Older Americans Act is reauthorized by funding area agencies to establish a repository of information on diagnostic and social services in their geographical areas for Alzheimer's patients, to strengthen and establish self-help groups, and increase legal services to patients and families.

It may be quite awhile before science finds answers that will lead to cure or prevention of Alzheimer's disease and related disorders. Meanwhile, it is urgent that we address the very real, very immediate needs of both the Alzheimer's patients and those who care for them—all victims of these diseases. Perhaps by providing the vital day-to-day support needed we can lessen the tragic impact of this most dreaded of diseases.

Chairman HEINZ. It is now my pleasure to turn to Dr. Butler, who, at the young age that he did, retired from Washington, D.C., to greener pastures.

Dr. BUTLER. I would like to submit my testimony for the record, if I might. I would like to focus upon research.

Chairman HEINZ. Without objection. [1]

STATEMENT OF DR. ROBERT N. BUTLER, BROOKDALE PROFESSOR OF GERIATRICS AND ADULT DEVELOPMENT, MOUNT SINAI MEDICAL CENTER, NEW YORK, N.Y.

Dr. BUTLER. I will argue that the ultimate cost containment and ultimate service will be to bring to an end this affliction of Alzheimer's disease.

Further, while we certainly cannot say that a solution is around the corner, there are enough exciting leads to make it reasonable, sensible, and prudent for us to expand the support of research. I could not help but reminisce, particularly, Senator, since you referred to my coming from the National Institute on Aging, to the beginnings of the Institute. I did a hand count of the number of grants involved in Alzheimer's. This is 1975. It is extraordinary there were only 12, totaling about $600,000.

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[1] See page 54.

So, although we have a long way to go, we now have $22 million in support of research on Alzheimer's disease. At that time, we identified senile dementia of the Alzheimer's type as a major national priority. I commend your thought of reinvigoration of a task force within the National Institutes of Health. NIA did develop an initiative and won an internal competition for the establishment of a specific effort to identify Alzheimer's disease as a major priority of the NIA, Neurology and Mental Health Institutes. That initiative should continue.

The reaction of the public to the identification of Alzheimer's disease as a major priority was absolutely astounding. The number of telephone calls, messages, contacts, from the media and the public were unbelievable and expresses profoundly the extent of concern among Americans in regard to this disease.

Several times this morning, there has been uncertainty about how many individuals suffer from Alzheimer's. That is because we have not had an adequate research base upon which to depend. The National Institute on Aging, and Neurological and Mental Health Institutes are supporting a series of population-based studies that will help us to know better the incidence and prevalence of that affliction.

We have had to extrapolate from data derived from Sweden, the United Kingdom, and from very old studies conducted in Syracuse, N.Y., and elsewhere.

My estimate is that about 15 percent of people over 65, about 4 million people, suffer from some degree of this disease.

Senator PRESSLER. Your estimation?

Dr. BUTLER. Fifteen percent. About half, as we learned this morning, in nursing homes suffer from this disease. Given the fact there are now more patients in nursing homes than there are in hospitals, we are talking about an extraordinary national problem with great personal and social cost.

In focusing upon research, I will be very brief and discuss five major areas of study.

One relates to neurotransmitters. Those are chemical messengers that convey information from one nerve cell to another, for example, memory. A brain definition, acetylcholine, a very important chemical, is the basis of one of the most attractive and interesting hypotheses available to us. Work at Einstein, Hopkins, Mount Sinai, and elsewhere, has been directed to trying to identify the nature of the deficit.

In my Washington days, I tried to make contact with our military chemical warfare, because they do work in neurotransmission. I have wondered, and perhaps you could help in this regard, how we might find out if there is unclassifiable information related to neurotransmission in this affliction.

An interesting finding of Dr. Kenneth Davis concerns a medication known since 1895. Physostigmine can provide a brief respite from the condition, very brief, but it is an important lead.

How might we be able to find a similar chemical which does not have the adverse side effects of physostigmine, but has a longer positive effect? That demonstrates a little bit the importance of further investigations into central nervous system neurotransmission.

The second lead is the topic of aluminum. I do not think any responsible person in the study of Alzheimer's disease is prepared to tell people to give up antacids, or antiperspirant, or put away aluminum pots and pans. We know that examination of bauxite workers, and others, involved in the extraction and production of aluminum do not have a higher incidence of Alzheimer's.

Once the primary lesion of Alzheimer's is established, however, it appears that aluminum concentrations do increase. Could it be that the removal of aluminum might have a beneficial effect? Could it be that nature is telling us something about the underlying condition by virtue of the superimposed effect of aluminum?

Third, genetics. We have known for a long time that there are familial forms of Alzheimer's. Therefore, we also want to understand the late-in-life penetrance of this genetic disorder.

We know from the examination of people by Heston, of the University of Minnesota, that there is a higher than expected association between Alzheimer's and Down's syndrome. Also, of individuals who are suffering from various types of blood cancer.

That, in turn, suggests the possibility of a chromosomal abnormality, which may not be genetic but congenital. It also suggests a possible role of the immune system, for example, the broad category of autoimmune diseases based upon the curious fact we may become allergic to our own body proteins. This is a major lead we must investigate.

Finally, the remarkable topic of slow viruses. Some years back, one of our Nation's most distinguished scientists, a Nobel Prize winner from the National Institutes of Health, found that a degenerative disease affecting the cerebellum was due to a slow virus.

I would bring to your attention a paper that summarizes this and brings it to your attention. [1]

While we may not have the cure, it does not mean the disease is not treatable. Some of the earlier speakers, not meaning to say this implied that there is no treatment possibility. There is much that can be done to maintain the appropriate stimulation level within the environment, to not overstress the individual, to make sure nutritional status is proper, and to continually maintain orientation and motivation of the person.

In terms of reimbursement, and the necessary reimbursement revolution that has been proposed here earlier, I think we have to recognize the possibilities of treatment. There is so much we can do. If we assume otherwise, we are failing to point out that there are many, many diseases which are not curable, including diabetes and yet reimbursement is provided.

Did Moses bring down from the mountain a special set of reimbursement to remain on the tablet forever? We must reexamine and renegotiate the reimbursement system as it bears on a variety of diseases particularly, as Dr. Libow points out, to bring it into conformity with the demographic resolution.

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[1] See appendix.

It was my pleasure recently, upon the request of a congressional committee, to call for a doubling of the amount of funds available for Alzheimer's disease.

I was pleased, Senator Pressler, to hear that you, Senator Heinz, and Senator D'Amato appear to agree. I regard the call for a doubling of research funding as a conservative suggestion, an appropriately conservative suggestion.

I think it would be foolish and counterproductive to the development of the field, to throw money at the problem. We do have properly trained neuroscientists. There are people who can use the money wisely. We do have exciting ideas as I have endeavored to describe.

We would not be purchasing a will-o'-the-wisp activity by doubling research resources.

There must be new funds, not coming out of the already existing efforts of the National Institutes of Health. Funds should be used for the development of a network of centers for Alzheimer's disease throughout the country.

You have to have stable funding. The example of slow virus, makes clear the problem of the usual 3-year funding cycle. You have to provide stable funding that will attract outstanding scientists.

There are efforts at developing teaching nursing homes; there are grants available for teaching nursing homes that would help provide educational opportunities for R.N.'s, M.D.'s, and researchers. We must pursue new forms of diagnoses. There are reversible conditions. We must recognize them directly, and properly diagnose and treat them, or we sentence people to an apparent irreversible senility that might be reversible.

We need to seek a simple clinical test. That is one of the several priorities we have.

Between 1946 and 1964, the United States developed the most wondrous and largest generation in American history, the baby boom. We cannot wait until the first baby boomer turns gray in the year 2011, to declare war on senility, or to produce an adequately trained cadre of geriatricians and geriatric nurse practitioners.

We have to make decisions well in advance. You cannot solve the problem of senility overnight.

In 1935, a March of Dimes was started. In 1961, less than 30 years later, the last polio epidemic occurred, the last thump-thump of iron lungs each spring.

I submit that senility could fall the way polio did, if we invest now, and I would submit that research would be the ultimate cost containment and the ultimate service. We do not have polio anymore. Thank you.

[The prepared statement of Dr. Butler follows:]

PREPARED STATEMENT OF DR. ROBERT N. BUTLER

I am pleased to participate in the hearing "Endless Night, Endless Mourning: Living With Alzheimer's."

As you may know, at the occasion of my being called upon to be the first and founding Director of the National Institute on Aging, I personally cataloged and examined the research grants directed to the understanding and treatment of Alzheimer's disease then supported by any of the Institutes of Health, [NIH] and Alcohol, Drug Abuse, and Mental Health Administration [ADAMHA]. There were only 12 research projects operative in 1975. This was extraordinarily disconcerting to me personally and professionally. The problem of Alzheimer's disease is massive and accounts for extraordinary fear and turmoil in many older persons and families, as well as costs an enormous amount of money for care in hospitals, and particularly nursing homes. I highlighted Alzheimer's disease and related disorders as one of the several premier priorities of the evolving National Institute on Aging. I also collaborated actively with the other Institutes. The National Institute on Aging was the key sponsor in creating the Health and Human Services Department-wide initiative in Alzheimer's disease. With the Director of the National Institute of Neurological Communicative Disorders and Stroke, we helped support the beginnings of the Alzheimer's Disease and Related Disorders Association.

Since that time there has been considerable progress in research directed at unraveling the mystery surrounding the cause and treatment of Alzheimer's disease. However, progress remains limited and the investments in dollars from both the private and public sectors is minimal indeed given the extraordinary economic and personal impact of this disease.

I have been asked to focus particularly today upon the state of research progress. I should like to submit my written testimony for the record. I would also like to make available to you a copy of a summary of present research progress which was published in the TWA Ambassador magazine, November 1982.[1] I offer it because it was written in nontechnical language for public understanding. It was written with Marian Emr of the National Institute of Aging's information office.

There are several important sets of findings which yield insight into the cause or causes of Alzheimer's disease. First and foremost, there are the data that relate to neurotransmission, specifically the system of transmitting information or nerve signals by the cholinergic system. Acetylcholine is the principal chemical. Its depletion or more accurately, the depletion of enzymes involved in the creation and destruction of acetylcholine has been established. Further, there are data showing destruction of the nucleus basalis of Meynert which is an important component of the cholinergic system. Drs. Peter Davies of Albert Einstein, Coyle, Price and Whitehouse of the Johns Hopkins, and Kenneth Davis of Mount Sinai, are among outstanding investigators who have contributed to the increasingly impressive body of evidence suggesting that a deficit in the cholinergic system is critical in Alzheimer's disease. So far, however, there have not been therapeutic breakthroughs although the Kenneth Davis work suggests that physostigmine (which is known to reduce the destruction of acetylcholine) does have relatively brief therapeutic effects. I have wondered if there might not be information available through our military chemical warfare that would suggest other chemicals that would have similar effects to physostigmine but would last longer and cause fewer side effects. I do not mean to be fanciful in this suggestion but it could be that contact made at the highest levels could determine if there might be some appropriately unclassified information that would bear upon neurotransmission in this disorder.

It is certainly likely that neurochemical, functional, and structural elements in the central nervous system other than the cholinergic system participate in the pathogenesis of Alzheimer's disease.

There is enough information to justify major attention being directed to support research and research training in the neurosciences directed toward aging and to exploit these important leads.

Some members of the public have become uneasy over reports of the role of aluminum in Alzheimer's disease. There is no reason at this time to stop using aluminum utensils, antacids, or antiperspirants. Aluminum is the third most common element in the universe, following oxygen and silicon. There is no evidence to suggest that industrial workers involved with aluminum extraction or production have a higher incidence of Alzheimer's disease. Nonetheless, there is some suggestion for a secondary role in Alzheimer's disease. Putting it simply, there may be an increased deposition of aluminum in lesions created by the disease process. It is unclear that reducing the opportunity for such deposition or efforts at removal of aluminum deposits would have any therapeutic benefit, but it is important work that must proceed. Drs. Donald Crapper-MacLachlan and Daniel Perl are among those whose work has contributed to our understanding of aluminum concentrations and effects in the central nervous system.

It has been known for many years that a familial form of Alzheimer's disease occurs; that is, some families unfortunately have a high genetically determined occurrence of the condition. It has been estimated that the presence of a family history of Alzheimer's doubles one's chance of developing the condition if one lives long enough. The gene is expressed with greater age. There are epidemiological studies (for example, by Heston of the University of Minnesota) that show a higher than would be expected association of Alzheimer's disease with Downs syndrome and with a variety of blood cancers. Such findings encourage us to chromosomal abnormalities and immunological phenomena. There had been reports of antibrain antibodies in Alzheimer's studies.

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[1] See appendix.

Other prominent theories that have received attention relate to slow acting or unconventional viruses which have been shown to play a role in other central nervous system diseases.

There has been a recent suggestion that an antagonist of opium called naloxone may improve memory function in patients suffering from Alzheimer's disease. It is known that opiate drugs can create forgetfulness in studies of laboratory animals, and further that opiate antagonists, can reduce the adverse effects in animals.

So far I have discussed biomedical research in Alzheimer's disease. I would like to turn now to behavioral research, helpful to both the individual and to the family. We know that behavioral techniques, orientation procedures, and motivation incentives all help to maintain and preserve intellectual capacities of patients suffering from this disease, even though they cannot reverse the underlying condition. This is an extraordinarily important point because although Alzheimer's disease remains incurable, it is not untreatable. This was true even before sophisticated behavioral research was introduced. The phenomenological, descriptive observation of psychiatrists, neurologists, psychologists, and others have made clear that much can be done to help patients suffering from this and other serious brain diseases.

This has implications for health policy, specifically reimbursement. There are many diseases that are not curable but are treatable and third-party payers including medicare do reimburse for such treatment. The victims of families with Alzheimer's disease have not enjoyed such an advantage. Thus, it is important to reconsider this distinction between curability and treatability. Much can be done to help Alzheimer's victims, which emphasizes the importance of behavioral as well as biomedical research.

It is also essential to direct attention to health services research, specifically the development of comprehensive sophisticated methods of assessment as well as environment supports. Some nursing homes, proprietary and otherwise, are beginning to develop special units for Alzheimer's disease which obviously can be of great help to families. With the introduction of major interventions of this type (which will ultimately cost a great deal of money through reimbursement), it is critical that controlled clinical trials of effectiveness be undertaken.

We all hope, of course, that a specific and simple chemical indicator of this disease or set of diseases will be discovered soon. Up to now diagnosis is made by exclusion, a necessary exclusion because there are conditions which are reversible and effectively treatable. It is essential that we develop a simple diagnosis, because unfortunately, at times, the condition of Alzheimer's disease is overdiagnosed; for example, by misinterpreting brain atrophy as a result of computerized axial tomography and thereby frightening the patient and family unnecessarily. Research in assessment is of great importance.

American families remain the No. 1 caretaker of their older family members including those that are impaired, for example, by Alzheimer's disease. European experience suggests that when respite for the family is available, it is possible to maintain the impaired person at home even longer. Thus another important part of health services research would include the evaluation of respite activities.

Research is a slow process. Commonly, however, information gained may have great clinical effectiveness even though we may not fully understand the cause of the disease in question. One need only list some of the most commonly used medications, from aspirin to penicillin, to realize that they may have useful effects upon diseases we do not fully understand. Moreover, we do not fully understand the mode of action of many pharmacological agents.

Were we able to enhance memory by even 10 percent in cases of Alzheimer's disease we would save society an enormous amount of money. It is memory and other intellectual functions that make it possible for us to remain in our own home. Our mind is our most critical means of personal adaptation. That is how we remember to take medications, eat properly, not leave the stove on, among other things.

I am personally and professionally grateful for hearings of this type because it helps to identify in a forthright manner the importance of a disease that has such devastating consequences.

Alzheimer's disease is the most common form of senility and it helps create a negative imagery about old age and frightens all of us who would grow older.

Clearly we must move rapidly to better understand and treat Alzheimer's disease. The post World War II "baby boomers" constitute the largest generation in U.S. history. If we do not understand and are not better able to treat senility by the time that wondrous generation begins to grow old after 2011, we face an even more extraordinary increase in the numbers of individuals in hospitals and nursing homes than is the case today. It would give further force to the statement of the distinguished scientist Lewis Thomas that Alzheimer's disease is "the disease of the century."

Chairman HEINZ. I do not know how Sam feels about following that, but we turn the floor over to him.

Mr. SADIN. We at the Brookdale Center on Aging at Hunter College have worked with Dr. Butler. I can only say it is good to know that he is here to make the kind of presentation which he has made. The note of optimism that he has sounded is one with which Dr. Dobrof and I would like to associate ourselves.

In every presentation which we made on the subject of health care, we are aware of the importance of the question: "How will it be paid for?" We are not unmindful of costs. We do not suggest that Government take sole responsibility for the provision of health care for older Americans. We believe that a partnership between family, community, government, voluntary agencies, and the private sector is necessary.

We are eager to participate with you in designing methods and services which result in efficient, economical health care systems; keeping in mind however, that services cost money and increased services will be required in the future.

Chairman HEINZ. If anybody in the audience finds out a way to provide services for free, let us know.

Mr. SADIN. That promise is often made, that costs will be cut and that services will be increased and improved. It is difficult to see how this can be done.

Mr. Chairman, with your permission, I would like to read all of my prepared statement. It will only take a few minutes.

Chairman HEINZ. Please proceed, Mr. Sadin.

STATEMENT OF SAMUEL SADIN, DIRECTOR, INSTITUTE ON LAW AND RIGHTS OF OLDER ADULTS, BROOKDALE CENTER ON AGING, HUNTER COLLEGE, NEW YORK, N.Y.

Mr. SADIN. My name is Sam Sadin and I am testifying on behalf of Rose Dobrof, director of the Brookdale Center on Aging of Hunter College and myself. I am director of the Center's Institute on Law and Rights of Older Adults.

As a preface to our testimony, we want to congratulate you, Senator Heinz, and your colleagues on the committee, for the leadership you are taking in bringing the tragedy of Alzheimer's disease to public attention. We congratulate you also on your selection of Jewish Home and Hospital as the site for these hearings. This home is one of Hunter College's most valued clinical training centers for our social work, nursing, and other health professions students and we are proud to call Mitch Waife and Leslie Libow both colleagues and friends.

We want to make one other prefatory comment: In both the Senate and the House there have been occasions when questions were raised about the appropriateness and efficiency of having committees on aging. We remember several years ago receiving a letter from then Senator Adlai Stevenson, explaining why he believed that the committee that you now chair Senator Heinz, was not necessary. We, in concert with others, protested against the plan which would have abolished this committee. We argued that such a committee was an essential vehicle for bringing to the attention of the Congress, the executive branch of Government, and the general public, the situation of older people and the problems they face. I would suggest that today's hearing is a precise illustration of our point, and represents the Senate committee system at its best.

Now to the subject of Alzheimer's disease. We do not have the expertise nor does the committee have the time for us to make a comprehensive statement. We have, therefore, selected a few aspects of the problem for discussion. First, we believe that Alzheimer's disease is an unmitigated tragedy which is a blight on the life of the victim and equally on relatives and friends who must bear witness to the inexorable progress of the disease and who must care for and care about the person their loved one has become. The tragedy is inescapable and Government policies and programs cannot change that fact. But we have today a situation in which public policy not only does not help, but indeed, its consequences are to add to the pain and sorrow families and old people experience. Daily we see spouses, children, and other relatives trying to do what is right and what is best, but unable to find their way to the services they need or if the path is clear, the service may not be there or it may not be available, because of eligibility requirements and other regulations.

It simply is the case that medicare, designed as a program to socialize the cost of short term, acute episodes of illness, does not cover chronic, irreversible, progressive conditions like Alzheimer's. Long-term custodial care is not covered either by medicare or by private insurance plans; only medicaid covers this kind of care. As a consequence, we are seeing the tragedy of aged couples or widows being pauperized by this illness. We are seeing pauperization as the price of medicaid eligibility; the term "spend-down" may sound better, but make no mistake—what we are talking about is pauperization in old age, of hard-working American citizens.

And even if the Alzheimer's patient achieves medicaid eligibility, that eligibility is no guarantee of service delivery. Placement in a long-term care facility sometimes becomes necessary, but nursing homes are often reluctant to accept Alzheimer's patients. Such patients are frequently "heavy-duty" cases, requiring substantial hours of nursing care. Most homes for quite understandable reasons, want a mix of patients, a balance between the intact and the impaired, between heavy-duty and minimal-care patients. The Alzheimer's patient for whom placement is the appropriate decision may languish in an expensive acute treatment hospital bed. Or, she may be at home with family members trying desperately to provide the care that is needed and still carry their other family and work responsibilities. And many families are faced with the painful necessity to accept placement in a home not of the quality they want for their beloved relative, or in a location which makes frequent and regular visits difficult, at best.

We are not suggesting that the Government should take over all the responsibility, either for the provision of care or for its financing. We believe that a partnership between the family, voluntary agencies and neighborhood organizations, and government is necessary. Nor are we unmindful of fiscal constraints. We believe, however, that the increasing numbers of Americans who are living to be very old means that the number of Alzheimer's sufferers is likely to increase in the coming decades and, therefore, costs are likely to increase also. But we also believe that the systems of care could be rationalized, that the separation between medicare and medicaid bridged in some way, so that eligibility for long-term and custodial care no longer be income tested. Moreover, we believe that even a modest increase in funding for preventive services could reduce both the human suffering and the budget expenditures which result from undiagnosed and untreated health problems.

You entitled this hearing "Endless Night, Endless Mourning: Living with Alzheimer's." We have said that we believe that the darkness and the grief are inevitable, but they should not be made deeper by the absence of a coherent and humane policy, or by systems that cannot respond to the calls for help from Alzheimer's patients and their families.

Both Professor Dobrof and I thank you for this opportunity to testify.

With your permission, I would like to comment on two matters which have been mentioned in earlier testimony today.

We urge the committee to examine the home-care provisions under title XVIII, parts A and B for the purpose of including custodial care at home or in an institution without the need for skilled care as a precondition and that home care be defined to include personal care aides and home attendants.

Long-term custodial care should be included as a benefit to be reimbursed under medicare without the skilled care and homebound provisions.

The principle of long-term custodial care ought to be included as an essential part of the medical program.

Chairman **Heinz**. You have touched on the subject which you are going to become more involved in after this hearing. That is, you and Mr. Strauss.

Mr. **Sadin**. Our experience has shown us that there is a widespread need for long-term care under medicare.

Chairman **Heinz**. You are really on the hook and are getting in deeper.

Mr. **Sadin**. However, the Health Care Financing Administration, though, during the course of the last year, reduced the number of hours available for the average medicare home-care patient, as little as that was. We believe that this was done without the statutory authority.

We believe that the current interpretations of reimbursement for home care is more restrictive than is provided for in the statute and the regulations and does not necessarily result in cost savings.

I would suggest that the legislation which Trish Neuman sent to us, S. 1301 and S. 1614, should be more widely known. It does not appear that these bills are being given adequate consideration.

Finally, the matter of spousal impoverishment is crucial for many families.

Chairman **Heinz**. I think that was a point powerfully made earlier.

Mr. **Sadin**. Between inflation and long-term illness, many families are going to be impoverished after having worked a lifetime and saved a modest amount of money for their old age.

It would not seem to be in the national interest for us to impoverish such families. Perhaps a method can be found by which the spouse remaining at home does not become impoverished or that the rate of impoverishment be slowed.

The reimbursement revolution which Dr. Butler referred to is on the way. I think the question is how will it occur. It is going to come. It will either result in sharp reductions, denial of care, greater costs, or it will be guided by a rational system where it can be possible for a committee like yours to introduce a semblance of order into what is now a disordered, fragmented, and anarchistic system.

Medical technology is developing at a rapid rate. We pay for it in our health care bill one way or another.

This will result in more people living longer, and that will result, unless we reach a medical cure, in more Alzheimer patients and more chronic illness, and more need for custodial care.

We have to look at that realistically and say that a civilized nation cannot afford, either in terms of its conscience or dollars, to deny the last years of health care which are undoubtedly going to be required as we get older.

Many of us here are eager to help you with our time and our organizations.

Thank you very much for the opportunity to testify.

Chairman **Heinz**. I will yield to Senator Pressler who is pressed for time. I want to take 30 seconds to summarize what I think you have said, or one thing many of you touched on.

What we have learned so far is that it is literally better, if you are predestined to become an Alzheimer's patient, it is better to be very rich or very poor, but do not be a member of the group in between.

Mr. **Sadin**. Even if you are poor, it is very tough.

Chairman **Heinz**. Second, we have learned that it is better to have cancer than Alzheimer's, because we take care of you if you have cancer. That is an acute illness.

Third, for heaven's sake, either do not ever get married or, I mean this with obviously a total ironic sense, have the good fortune of having your spouse die before you, because if you do not, she will end up being impoverished.

Those are not exactly three of the best pieces of news to be faced with if you are faced with the reality of becoming an Alzheimer's patient and being afflicted with that disease.

I think it should summarize for our colleagues exactly how confused our present health care system is. It reflects a confused parentage, growing up over the years.

It also, I think, lends great credence to what Dr. Butler was saying a few minutes ago. I have more questions about that, but I will yield to Larry.

Senator Pressler. I apologize for having to leave. This panel has given a stunning performance, in my opinion.

I think what you have said we can use before the Appropriations Committee, the Finance Committee, and the Aging Committee. I do have a question. The point is, in the Senate we have always hesitated to earmark funds for the National Institute on Aging.

Last year, I suggested we earmark an increasing amount of funds for Alzheimer's research.

Some people say that you put handcuffs on us if you do that.

Where should we leave this decision? With the Federal budget being the size it is, we have to categorize things that we have to work on. Do we increase the overall funding for the National Institute and let them make their professional judgments?

Will they make the correct professional judgments if we do not earmark. The whole business of earmarking funds for research fascinates me. I had a debate on this on the issue of earmarking with the Senator from New Mexico. He opposed and I supported.

How do we resolve that?

Dr. Butler. It is difficult. I have been associated with NIH since 1955, off and on. NIH is the creation of Congress and is interested in the directives of Congress. Part of the problem is that when you say that *x* amount of money should be allocated for disease *x*, it is often the case that the year before Congress suggested allocations for other diseases. Other groups that suffer greatly, say, from Lou Gehrig's disease may have pushed for a previous congressional appropriation to "earmark the money."

It becomes extraordinarily difficult. I wanted to have our scientists know more about how drugs work in the aging body. While NIA Director I almost made the mistake of earmarking a certain amount of money under a request for projects for studies in pharmacology.

I am glad that I did not. The proposals that came in were so poor that had I been obligated to spend *x* amount of money, I would not have been responsibly using the taxpayers' money.

We need an intermediate ground, with language that expresses clearly, how you wish money to be spent, that you urge something but do not require it, because it may turn out to be a wasteful use of money.

I have left to last the most important aspect, the need to add money. We have now identified Alzheimer's disease as the No. 4 or 5 cause of death. We have seen that it has enormous economic repercussions on our society. We see that the amounts of money devoted to its understanding are infinitesimal compared to many other diseases that are far less common.

Senator Pressler. Thank you.

Chairman Heinz. May I ask that you all express your gratitude, as I have, to Senator Pressler.

Bob, you have urged that the Congress add roughly $22 million more or more than $22 million. Add that to the NIH budget.

Dr. Butler. Yes.

Chairman Heinz. For Alzheimer's. As I think you heard me say at the press conference, it seems to me that there also needs to be more than just money added to the Alzheimer's research effort. I was fortunate, at about the same time you started at NIH, to be involved in Paul Rogers' House Subcommittee on Health and the Environment, to be involved with the awakening effort on diabetes.

Would you feel that the composition, the creation of a task force along the lines of that diabetes task force would be appropriate? If so, who should lead it? What should be done to stimulate the organization through money as well as leadership?

Dr. **Butler**. I think your concept of a task force is a good one. I do not think I am self-serving to suggest that the present Director of the National Institute on Aging be the key leader in the task force.

Chairman **Heinz**. Not self-serving any more.

Dr. **Butler**. Exactly. I feel that it is a disease of aging. It is the responsibility of the National Institute on Aging to be concerned with the many debilities that afflict older persons.

It did take historic leadership for the identification of the disease as a national priority. It was my contention—that I presented some months ago before the House committee—that the NIA alone should not receive funding, but the Mental Health and Neurology Institutes and Allergy and Infectious Disease Institute, because of the slow virus theory.

Alzheimer's disease is potentially a multicausal illness.

Chairman **Heinz**. I would agree. That is why I asked as between NIA and NIH.

Dr. **Butler**. As you know, the National Institute of Mental Health is part of the Alcohol, Drug Abuse, and Mental Health Administration. I think work on Alzheimer's should be a collective effort. I think there should be a chairpersonship. I think we should keep watching the literature and research, and that while there should be some healthy competition among the institutes, they should collaborate as well.

Chairman **Heinz**. Are you too young to remember the heart, cancer, and stroke program, which became the RMP program, for reasons I do not understand. Is that a good model?

Dr. **Butler**. If I do remember correctly, that concerned community and other services, and it was not only research.

Chairman **Heinz**. It was partly, as I understand it, and I was not in public service at the time, to try and mobilize the medical profession to use the findings and advances with respect to those diseases.

Dr. **Butler**. Yes. There may be other models. Perhaps, there are more useful models in research.

If you were thinking of broadening an Alzheimer's disease initiative to include services and education, you might want to move along an NIH direction. If you are talking only about research contributions, the model might more appropriately be the Institute of Environmental Health Sciences and the impact of environment health hazards.

The diabetes task force, the trans-NIH nutrition and genetics efforts have worked reasonably well.

There are pretty effective policy approaches used at NIH and NIA that have led to results that have been effective.

Chairman **Heinz**. I thank you for your comments, Commissioner Sainer. Thank you for pointing out very clearly some of the difficulties we have with our system.

Mr. Sadin, I will thank you now for things that you will do in the future as well as what you have done.

I thank you all very much.

I commend all of our witnesses.

I think it has been an excellent session.

[Whereupon, at 1:30 p.m. the hearing was adjourned.]

By Robert N. Butler, M.D.,
and Marian Emr

Alzheimer's Disease:

An Examination

Understanding the most common, debilitating, and early form of senility.

At the very peak of his career, an attorney in one of the nation's top law firms begins to make surprising errors in fact and judgment. The changes precipitate more serious deterioration including alterations in personality, behavior, and intellect.

An accountant, who together with her husband has built a successful and highly respected firm, can no longer subtract seven from ten.

A successful businessman, a top executive in his firm, gradually loses interest in his work, his friends, and previously pleasurable activities. His memory fails. Easily confused, he frequently wanders away and becomes lost. Reluctantly, his superiors ask him to resign.

While the symptoms differ, each of these individuals suffers from the same disease—senile dementia of the Alzheimer's type (SDAT). A neurological disorder with no known cause and no known cure, SDAT afflicts some 1.5 million Americans, including five percent of the elderly population. Because of the growing number of elderly Americans, SDAT has been called "the disease of the century." When it strikes, individuals who were once resourceful and capable eventually become totally dependent. The process is so insidious that colleagues, friends, and relatives unconsciously begin to assume responsibilities that were once routine for the afflicted individual: a spouse learns to balance the checkbook, a secretary or a coworker provides extra support to get the ailing individual through the work day. Even close acquaintances may dismiss bizarre behavior changes—even as they begin to unconsciously avoid socializing with their friend. Often years go by before the peculiarities of behavior and the declining intellect are viewed as the symptoms of disease and diagnosed as SDAT.

The most common and debilitating form of what is popularly termed "senility," SDAT is called Alzheimer's disease when it strikes middle-aged adults. It was first described in 1906 by a medical scientist named Alois Alzheimer. According to Alzheimer's account, a patient began to experience loss of memory and disorientation followed later by depression, hallucinations, and eventually severe dementia and death. During a post-mortem examination of the patient's brain, he found that it was severely atrophied and that nerve cells in the cerebral cortex or outer layer were riddled by distorted protein fibers. Alzheimer called these jumbled fibers neurofibrillary tangles, and they have since become the hallmark of the disease bearing his name. Ironically, this "old age" disease was first studied in affected middle-aged adults; the patient Alzheimer described was only 51 years old. Not until two decades ago did scientists discover neurofibrillary tangles and other Alzheimer-type pathological changes in the brains of "senile" individuals, thus linking Alzheimer's disease to the most feared of all maladies of the elderly.

While no one knows for sure what causes SDAT, biomedical scientists are pursuing several leads. One of the most promising links chemical changes in the brain with the development and progression of Alzheimer-type dementia. For some time, experts have known that victims' brains show a precipitous loss of the enzyme choline acetyltransferase. In a healthy brain, this enzyme plays a key role in the production of acetylcholine, a neurotransmitter responsible for conveying the nerve impulses governing memory. Initially, these findings stimulated experiments in which research volunteers were given dietary supplements or drugs containing choline, one of the two elements necessary for the synthesis of acetylcholine. Magazine and newspaper articles and other

Robert N. Butler, M.D., whose book Why Survive: Being Old in America *won the Pulitzer Prize in 1976, recently left his position as director of the National Institute on Aging to start the nation's first department of geriatrics, at Mount Sinai School of Medicine. Marian Emr is a public information specialist at the National Institute on Aging.*

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publicity encouraged increased consumption of choline, which is found in the vitamin B complex and concentrated in such foods as eggs and meat. Lecithin, the dietary source of choline, was promoted as a "memory food." Unfortunately, there is little significant evidence that either of these substances can enhance memory. Even scientists, who utilize nearly pure concentrations of lecithin in their experiments, have been generally disappointed with their findings.

Studies of drugs that attempt to preserve quickly degenerated, limited supplies of acetylcholine in the brain have been more successful than those designed to overload the system with choline. At several university medical centers, investigators are finding that the drug physostigmine has a positive effect on the memories of people with SDAT and also those complaining of age-related memory loss. Much work remains to be done before we find a drug that might be more effective than physostigmine, and safer to use over a long period of time. Still, preliminary results of these tests are very positive. Also, scientists have recently discovered a specific population of cells in the base of the brain that are major producers of acetylcholine–and that are selectively destroyed in the brains of SDAT victims. This finding is likely to encourage other investigators to invest more time in studies of the chemical basis of SDAT.

Scientists are also interested in another change occurring in the brains of Alzheimer victims; it involves trace metals. Aluminum has long been recognized as a neurotoxic agent. In fact, a number of brain disorders, most notably "dialysis dementia," are marked by increased aluminum concentrations in the brain. The first findings of a link between elevated aluminum concentrations and the neuropathologic lesions of SDAT were announced by Canadian researchers in the mid-1970s. These tests showed excess aluminum in certain regions of the SDAT brain known to contain large numbers of neurofibrillary tangles. Over the years, however, the association between aluminum and SDAT has been controversial. Some studies have failed to confirm the high levels of aluminum noted by the Canadians, others have suggested that aluminum accumulates naturally in the aging brain. However, the most recent studies, using an extremely sophisticated and sensitive method to analyze the elemental content of cells from SDAT and normal brains, have revealed an unmistakable link between the pathology of SDAT and aluminum. Only neurons with neurofibrillary degeneration contain detectable amounts of aluminum; the element rarely appears in normal nerve cells even when adjacent to tangle-bearing nerve cells with high levels of the element. These high levels of aluminum are probably not causing the disease, but they do become apparent in its development and may contribute substantially to its symptoms. Tests are now underway to determine whether it is practical, effective, and safe to use chelating agents to bind the aluminum and remove it from the body.

Children and other relatives of SDAT patients often wonder whether the disease is hereditary, and, not surprisingly, a third theory proposes that a gene or a group of genes cause or promote the condition. The first studies of families in which one person had senile dementia showed that the chance of a relative developing the disease may be four times greater than the likelihood of it appearing in the general population. The risk appears greatest, however, among families affected by classic, early-onset Alzheimer's disease. In these cases, the course of the disease is often short and seems more severe. Down's syndrome and several other disorders linked to chromosomal abnormalities also seem to occur more frequently in these families. Estimates for the risk to children are not available, but the risk to brothers and sisters of individuals who become ill after age 70 is hardly different from that to the general population.

SDAT may be among the nervous system diseases that are believed to be caused by slow-acting transmissible viruses. These are not viruses in the conventional sense of the word, but ones whose damaging effects take years to develop. In the late 1960s, material from several patients with rare familial cases of SDAT produced degenerative brain disease in chimpanzees and provided the first hint that dementing disorders might be caused by one of these hidden viruses. Although investigators have been unsuccessful in their attempts to reproduce or corroborate these findings–or to isolate the virus–the initial studies have spurred further explorations. The recent discovery of submicroscopic proteinaceous infectious particles ("prions") might stimulate increased interest in this theory. It appears that prions may take as long as twenty years to induce brain damage and that they can be linked to at least one form of degenerative brain disease that has long been the focus of slow-virus investigations.

Research on immunology may yield insight into the cause or causes of SDAT.

Research on immunology may yield insight into the cause or causes of SDAT. Some investigators believe that in old age the immune system loses its ability to recognize elements of the host's body and begins to attack them. Age-related changes in the immune system–a system that reaches the peak of its potential at puberty and then begins a lifelong decline–have been tentatively implicated in the development of a number of disorders of old age. Antibrain antibodies may be among the causes of degenerating nerve cells in SDAT.

Of course not everyone who forgets things has senile dementia of the Alzheimer's type. Of every ten elderly patients who are confused, disoriented, and suffering from serious forgetfulness, about half are SDAT victims. Another two or three might suffer from multi-infarct dementia (MID) or from SDAT in combination with MID. In multi-infarct dementia a series of minor strokes destroys masses of brain tissue. Previously many physicians thought that hardening of the arteries was the major cause of "senility" in old age. In fact, arteriosclerosis is not common and is just one of many vascular disorders that have the potential for causing dementia. Any blockage that deprives the brain of blood and oxygen can cause these small, seemingly imperceptible strokes and, eventually, dementia.

The remaining two patients in the hypothetical group of ten may be suffering from any of some 100 reversible physical conditions that result in devastating, but often temporary, changes in memory or intellect. Infections, fevers, cardiovascular problems, metabolic disorders such as hypo- or hyperthyroidism, or toxic reactions to drugs, for example, can temporarily upset the normal functioning of extremely sensitive brain cells. If untreated, such medical emergencies can produce permanent brain damage and possibly even death.

Similarly, emotional problems can mistakenly be confused with irreversible brain disease in old age. Depression, loss of self-esteem, loneliness, anxiety, and boredom are more common as elderly persons retire or experience, often simultaneously, the deaths of relatives and friends, failing health, or other crises.

Of a population of 25 million elderly Americans, only three to four million experience intellectual problems. Of these, only a fraction are so severely debilitated that they can no longer care for themselves or remain in their own homes. Nevertheless, the notion that "senility" is inevitable pervades American culture. Apparently,

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having grown older in a society that expects little from its aged and everything from its youth, many people become anxious when they notice changes in their abilities to remember.

It is important to realize that, while forgetfulness may be more common among the elderly, it can occur at any age. Thus it should not cause undue anxiety if a person is unable to recall relatively unimportant information or parts of an experience, such as a name, a place, or a date, while remembering the experience itself. This "benign" memory loss might even vanish if the individual attempts to recall the information subsequently. Only when the experience itself is forgotten, or when forgetfulness diminishes the victims' ability to cope with family- and work-related responsibilities, should medical consultation and care be sought.

Fewer than one-sixth of all elderly Americans experience intellectual problems.

If the conclusions of research on the aging brain conducted during the past two decades were better publicized, they would do much to allay our fear of growing old because they reveal some reassuring facts about the physiology of the elderly. For example, recent studies show that the rate at which oxygen and blood flow through the brains of healthy elderly adults is no different from the rate in healthy young persons, even sometimes in those 50 years younger. Thus it is a myth that hardening of the arteries is a natural concomitant of age. As previously mentioned, arteriosclerosis does have a devastating effect in depriving the brain of essential nutrients, but the disease is far less common than SDAT. Furthermore, tests of brain activity suggest that the healthy aged brain works as hard and as efficiently as the healthy young brain. This is a preliminary conclusion of studies employing sophisticated new machinery to enter and study specific regions of the living human brain. In positron emission tomography (PET), the subject receives an injection of a radioactively marked analogue of glucose, the main source of the brain's energy. The analogue is similar enough to this simple sugar to get past the blood-brain barrier, the brain's natural defense, but is then trapped within the brain because it cannot be metabolized. The extent to which specific brain regions take up the tracer is measured by external counters on the skull that are sensitive to the small amount of gamma radiation emitted. This information is then processed by computer, and the rate of glucose utilization represents the levels of activity of various brain regions.

Previously, cross-sectional tests of mental and intellectual function had concluded that intelligence declines with age. Now, newer "longitudinal" studies that have been tracking the same individuals over extended periods of time have concluded that the majority of people maintain–or actually raise–the level of their intellectual competence as they grow older. This method of testing may favor the survivors who return to be tested year after year. Still, the results suggest that mental decline, when and if it occurs, happens later in life and is not as serious as was previously thought.

The inevitable loss of some 50,000 nerve cells each day after the age of twenty may or may not be responsible for intellectual decline in old age. Yet, despite this loss, at least some parts of the brain continue to grow as long as a person lives. This growth can be seen in the dendrites, the branchlike extensions through which the cell body receives virtually all messages from cells in other parts of the body. Perhaps at some point the brain cells that are regressing and dying begin to outnumber the cells that are surviving and growing, but it is encouraging to note that the brain seems to have a unique, built-in protective mechanism that allows it to compensate for the loss of some of its cells over time.

If there appear to be increased intellectual problems, particularly memory problems, as a person ages, it may be due to difficulties in acquiring new information, storing it away with all the learned material of a lifetime, or retrieving it quickly. Difficulties in acquiring new information may be caused or promulgated by visual or hearing problems. A person suffering from presbycusis (the common age-related loss of ability to hear high-frequency sounds) may have problems hearing human voices or interpreting speech, for example. Failing concentration or lack of motivation can also prevent proper registration of new information. The ability to store information may be compromised by increasing susceptibility to the effects of interference. The older central processing system seems less able to handle the overload of stimuli created by the thousands of messages the body receives every minute. As a result, information can by pushed aside by newer incoming information. Reaction speed is one aspect of intelligence that may indeed decrease with age. Therefore, even if information is properly acquired and stored, an older person might be slower in searching for, recovering, and producing that information from memory.

It is reassuring, however, that none of these age-related changes appears to be insurmountable until extreme old age. Older people often compensate for benign forms of memory loss by keeping notes, establishing routines, and planning ahead. In laboratory tests, scientists are successfully training older people to use learning techniques that include organizing new information, rehearsing it verbally, or linking what needs to be remembered to some visual image. This may seem like gratuitous advice since most people routinely use simple tricks or clues to remember someone's name or some other bit of information. However, research shows that if older persons are allowed to study new information in any manner they choose, they are unlikely to use any clues voluntarily. In one study, a group of older volunteers was encouraged to take an imaginary walk through their homes, stop at a set number of places along the way, and practice associating some bit of information with each place. The majority of the subjects later successfully recalled the new information they had been given using these visual reference points.

Until researchers can determine what age-related memory loss is normal–and what can be done about abnormal changes–there are a number of clues to improving memory. These include taking plenty of uninterrupted time to learn new things, making sure that the environment's lighting and acoustics promote learning, concentrating on one thing at a time, and, above all, not becoming anxious if you can't remember names or facts as fast as you did when you were younger. Most older people are able to remember as well as they ever could; it may simply take more time.

At present, medical science offers no cure for SDAT or any of the so-called irreversible dementias of age. However, the proliferation of research studies on these disorders–many of them spurred by the establishment of a National Institute on Aging as part of the U.S. Government's National Institutes of Health in 1974–presents a hopeful outlook for the elderly of the future. Meanwhile, such private, nonprofit, voluntary health organizations as the Alzheimer's Disease and Related Disorders Association (360 North Michigan Avenue, Suite 601, Chicago, Illinois 60601) do a great deal to educate the public and public policymakers to the needs of the afflicted population and to offer support to those who were once told that nothing could be done to help.

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By Paul Froiland

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Alzheimer's Disease:

A Case Study

Part I: Louise

When Louise came home from grocery shopping, she found her husband Ted sitting on the patio, dressed in black wing-tip shoes and black stockings and wearing a bathrobe. Underneath the bathrobe he wore nothing but his underwear.

Before she went back to get a second armload of groceries she called out to him to see if everything was all right.

"Ted, I'm home," she said. She tried to sound bright and relaxed.

Her husband was sitting at a white metal table with an umbrella coming out of the center of it. He knows enough to sit on the shady side, she thought.

At the mention of his name he looked up and waved. His face was pasty white and his eyes looked sleepy. He appeared older than his 52 years, but he still had the outline of a once proud and muscular physique, and the eminence of gray hair.

He saw her at the patio door and waved again. "Hi, Louise," he said.

She thought it was very sensible, and went back to unload the car, but the outfit troubled her.

When she had put most of the groceries away she heard him calling her.

"Louise, bring me a drink," he yelled, unnaturally loudly.

"All right," she said.

She poured him two-thirds of a glass of iced tea and diluted it with another third of tap water and some ice cubes. He thought it was Scotch, and she let him think that, knowing that he also liked iced tea, and frequently couldn't tell the difference.

"Louise!" he called.

She opened the door. "Here it is, Ted. Here's your drink."

He took it from her, sipped at the top of it, and wrinkled his face grotesquely.

"This isn't a drink," he said. "I want a *real* drink."

He threw the glass abruptly down onto the flagstones, where it shattered. Louise jumped—just barely perceptibly—at the crash.

It's beginning, she thought; it's finally happening. He would deteriorate rapidly now. He would fail and fail. He would lose memory. He would have difficulty controlling his behavior. They would have to get a smaller house. He would have to be institutionalized. It all rolled out before her in successive panoramas of increasing misery. This was her Ted, the man who loved nature, who grieved at the death of a robin.

"Why don't you make me a *real* drink?" he asked her, his voice a loud monotone. "Where's the Scotch? Why don't you put Scotch in my drink anymore? I won't drink brown water."

She let him go on, her small, perfect face gathered in forced composure. When he had stopped, she said brightly, "Why don't you play a game of solitaire? I'll get a deck for you."

He turned his head suddenly at the suggestion. "Yes, solitaire," he said.

She brought out a deck of cards, pulling a rubber band from around it as she approached him.

"They're already shuffled," she said.

He took them from her and held them face down in his hands, looking a little uncertainly at them. Oh, dear God! she thought.

"Seven piles; first one face up," she said.

"I know, I know," he said, not looking up.

He began to deal the cards in the correct order, but slowly.

She remembered when his boss had first called her, the heavy thud inside when he said, "Louise, we've got to let Ted go. He's not performing any more. He forgets things. He seems to get confused at meetings, and his temper gets out of control. I think we can get a disability retirement for

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him, but he needs to be thoroughly evaluated."

Then the diagnosis: Alzheimer's disease: a continuous, progressive erosion of mental faculties for a period of seven to ten years, often ending in death from complications. That had been two years ago, and there had been only a mild impairment in his abilities since then, mostly forgetfulness and confusion—nothing entirely unusual or awkward or embarrassing.

But yesterday he had been impossible. They had been at the zoo, a place Ted loved to go—he had been a horticulturist for a large seed company, and had an undergraduate degree in animal husbandry—and he suddenly started laughing at the mandrills. He laughed and hooted and pointed at them for an unusually long time—Louise estimated it was close to a minute—it might have been half a minute; it felt to her like half an hour—and she could not divert his attention. When she finally got him home, he was furious that they had not seen all the animals.

She didn't know what to do. And now, this morning, for him to dress so strangely—he had always been able to remember how to dress himself.

"Louise, where's my drink?" he said abruptly.

"What?"

"When are you going to get my drink?" he said.

"Oh—right away," she said. "I forgot."

She went back into the kitchen, wondering how to handle it. Would he want Scotch or iced tea, and, since she couldn't give him Scotch, would he remember that it was Scotch he had asked for?

She poured him a full glass of iced tea, this time in a plastic tumbler. She didn't dilute it, to pretend it was Scotch. This time she was going to stay with iced tea all the way.

She brought it out to him. "Here's your drink," she said.

He was looking at her suspiciously.

"What kind of drink is this?" he asked, as he took it from her hand.

"This is what you asked for."

"I *know* what I asked for," he said. "I want to know what this is."

She knew he was bluffing, that he had already forgotten what he had asked for.

"It's iced tea," she said. "It's what you asked for."

"I asked for iced tea?" he said, half to himself. He took a sip and put it on the metal table, beyond the cards.

Louise saw that he had not gotten past putting the first seven cards on the table. She leaned over him.

"Good, Ted!" she said. "Now the next row. Skip the first one, then put the second one face up and all the rest face down."

He looked over his shoulder at her. "I know how to play solitaire," he said. "I haven't completely lost my mind; I can still play solitaire."

She wanted to withdraw with the hurt, but she knew he couldn't help it. Still, how could he be so coldly cruel to her? She wondered if the part of him that was still normal disliked her. She caught herself thinking and told herself to disengage. You can't respond to his every comment, she said to herself; half the time he doesn't know what he's saying. It's not a judgment on you.

She went into the house to get the broom and dustpan. When she came back, Ted was absorbed in his game.

Louise swept quietly around his feet, where the glass had broken. At first he didn't look up.

"Louise, what are you sweeping?" he asked in his loud monotone.

"Glass," she said.

He looked up. "Why are you sweeping glass?"

"So it doesn't get in the way."

"Does glass get in the way?"

"Sometimes," she said.

He went back to his cards. By now he seemed to be playing at a regular pace.

Louise went into the house with the broom and the dustpan full of glass and ice cubes. Their German shepherd Roo was standing inside the screen, looking out at Ted. She was a tan, almost apricot-colored dog that had been Ted's pet for the past several years.

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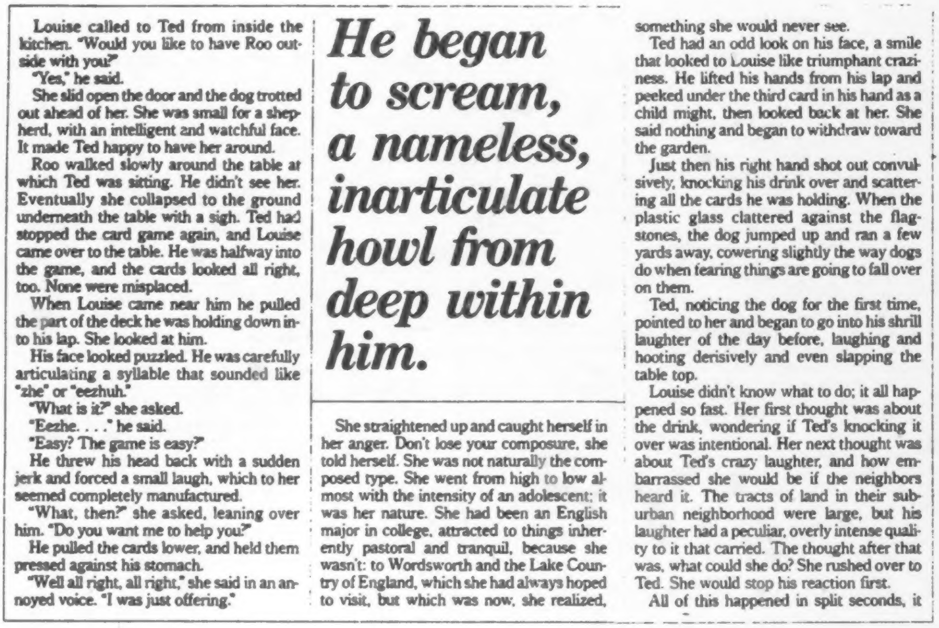

Louise called to Ted from inside the kitchen. "Would you like to have Roo outside with you?"

"Yes," he said.

She slid open the door and the dog trotted out ahead of her. She was small for a shepherd, with an intelligent and watchful face. It made Ted happy to have her around.

Roo walked slowly around the table at which Ted was sitting. He didn't see her. Eventually she collapsed to the ground underneath the table with a sigh. Ted had stopped the card game again, and Louise came over to the table. He was halfway into the game, and the cards looked all right, too. None were misplaced.

When Louise came near him he pulled the part of the deck he was holding down into his lap. She looked at him.

His face looked puzzled. He was carefully articulating a syllable that sounded like "zhe" or "eezhuh."

"What is it?" she asked.

"Eezhe. . . ." he said.

"Easy? The game is easy?"

He threw his head back with a sudden jerk and forced a small laugh, which to her seemed completely manufactured.

"What, then?" she asked, leaning over him. "Do you want me to help you?"

He pulled the cards lower, and held them pressed against his stomach.

"Well all right, all right," she said in an annoyed voice. "I was just offering."

He began to scream, a nameless, inarticulate howl from deep within him.

She straightened up and caught herself in her anger. Don't lose your composure, she told herself. She was not naturally the composed type. She went from high to low almost with the intensity of an adolescent; it was her nature. She had been an English major in college, attracted to things inherently pastoral and tranquil, because she wasn't: to Wordsworth and the Lake Country of England, which she had always hoped to visit, but which was now, she realized, something she would never see.

Ted had an odd look on his face, a smile that looked to Louise like triumphant craziness. He lifted his hands from his lap and peeked under the third card in his hand as a child might, then looked back at her. She said nothing and began to withdraw toward the garden.

Just then his right hand shot out convulsively, knocking his drink over and scattering all the cards he was holding. When the plastic glass clattered against the flagstones, the dog jumped up and ran a few yards away, cowering slightly the way dogs do when fearing things are going to fall over on them.

Ted, noticing the dog for the first time, pointed to her and began to go into his shrill laughter of the day before, laughing and hooting derisively and even slapping the table top.

Louise didn't know what to do; it all happened so fast. Her first thought was about the drink, wondering if Ted's knocking it over was intentional. Her next thought was about Ted's crazy laughter, and how embarrassed she would be if the neighbors heard it. The tracts of land in their suburban neighborhood were large, but his laughter had a peculiar, overly intense quality to it that carried. The thought after that was, what could she do? She rushed over to Ted. She would stop his reaction first.

All of this happened in split seconds, it

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seemed. Roo approached Ted again, barking loudly at him as she would have at a stranger who was behaving oddly, for Ted *was* suddenly a stranger to her, and her job was to guard against strangers.

Louise tried to distract Ted's attention by calling his name and standing in front of him where he could see her. When Roo began barking, he stopped laughing, and his face became horror-stricken. He began to scream, a nameless, wordless, inarticulate howl from deep within him.

Louise decided to risk coming up behind him, something that usually upset him, and touching him gently. She ran her hands lightly along his shoulders and called his name softly.

She felt his body relax, and she put her arms around his neck. He grabbed her forearms with his hands, grasping them tightly. She lay her cheek on the top of his head.

All the while she was thinking, Ted, my poor Ted. I don't know how to do this; I don't know what to do. I'm not a nurse, Ted; I don't know how to be calm. Oh, my poor, my dear Ted. What has happened to you? Where are you now? I love you, Ted; even now. Do you know that? Do you remember your Louise? Do you remember your sweet girl?

He kept his arms up, holding tightly to the hands around his neck, while a tear from her eye quivered like fresh dew, resting lightly on his gray hair.

Part II: Ted

There is something that is going to be exciting this morning. There's one thing exciting and one thing funny, and I can't remember either of them. It's just like a cloud around my head this morning.

The exciting thing is about going somewhere. I'm really excited. I'm going to put on my black socks and shoes—I think it's going away, going to the office, maybe. That's exciting.

My shoes are so stiff. Why are they so stiff all of a sudden? The laces are all dusty, too. That's odd.

Now I can't remember what I was doing—the exciting thing. . . . I'll just put my bathrobe on. You know, in the mirror my face doesn't look that bad. I know I'm sick, but I'm actually still pretty good-looking. *What did she say?* Aw, Ted, he said; she didn't say anything. He was looking at the ground. *Tell me what she said; I can take it.* I guess she doesn't want to go with you anymore, he said. *What? Did she say why?* She said you weren't good-looking enough. She wants to go with Jim Garr instead. *I knew it. I knew it.* Take it easy, Ted, he said. *I'm not upset. I wouldn't let that upset me. She's spoiled, that's all. She's a regular spoiled baby. I don't care if I never see her again.*

I can't find Louise or the nurse anywhere. Maybe she's doing the exciting thing and forgot about me. So—the exciting thing is going to the office that's what it is. I don't know why they want me back there. It seems I've been gone for a long time.

The garage smells just like gasoline. Someone has taken the car. Has it been stolen? I can't think too long or I'll forget where I'm going. I'm so frustrated today; it's so hard to keep a thought in my head.

So, anyway, the car is gone, and I can't find Louise to tell her. I'll sit in the living room a while, and talk to Roo. I just love animals. When the last person on earth has turned his back on you, the last dog on earth will still come up to you and offer to shake.

Animals—something funny about animals—that's the funny thing. I just can't remember it, though.

Roo is great, because I talk to her in my head, and I don't have to get the words to come out right. Isn't that right, girl? Aren't you Daddy's dog? Ah, that's my baby.

The patio table is cold beneath my arms. There's Louise. Hi, Louise! Now, what was I going to tell her? Something about animals, something very funny. I just can't remember it. Damn! I can't remember *anything* today.

I'm thirsty. Louise, bring me a drink. I keep asking her for a Scotch and water, and she never brings one. She always says I want iced tea when I asked for Scotch

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and water. I *know* I did.

Agkh! It's terrible. I won't drink that junk. I want a *real* drink. I just can't stand it, to drink that stuff. Now you swallow this, Teddy, she said. You're going to sit here until you've taken it. *But Mom, I can't get it to go down. It makes me choke.* Put it way back on your tongue. *I did! It made me choke.* Well, you're going to sit here until you swallow it. *I won't! I'll throw up. It's too big for my throat.* You have to swallow it. *No!*

Louise has the cards. I love to play solitaire. But I can't remember what you do during the first part. Louise says, "Make seven piles." Now, why is she telling me that? I know how to play solitaire. She treats me like a child.

She still hasn't brought my drink. Louise, where's my drink? Oh, here she comes, with my drink in a plastic glass, which I hate. But I'm more worried about what's in it. I keep asking for a Scotch and water, and she always brings me iced tea. And sometimes I can't remember what I asked for. I hate it that I can't remember. I just hate it. I put up the best front I can.

Now this one really tastes like iced tea–did I want iced tea? Louise says yes. Well, that's good.

So, let's see. Why won't she go away? I know how to play solitaire. I shouldn't get angry with her; I'm just so frustrated.

Red queen on black king. Ah, there's the ace of spades. I'll put that right up there: ace, deuce, three. Now why is Louise sweeping the patio? Louise, what are you sweeping? "Glass," she says, "because it gets in the way." I don't get that at all.

Now what–I can't remember what to do next. I can't remember what this card is. Oh, I could cry. To forget something that simple. Louise is watching me, so I'll just play more slowly and maybe I'll remember it. Now what is this card? It's an odd one; it doesn't seem to be like any of the others. I remember the first letter–it's a French kind of pronunciation–zhe, that sort of soft sound. It's like that other card, zhacque, like in that nursery song, "Frère Jacques," it's–Jack! That's the other card; this card starts with the same letter.

Louise is coming over. "What is it?" she says. She wants to help me. "Is it easy?" I laugh. Very funny. You know it's not easy. It's the farthest thing from easy. But she won't go away. She wants to help me. Well, I just don't want to be helped. I'll pull the cards into my lap; maybe she'll go away. *Go away.* Teddy, Mommy says that I should help you, she said. *I don't want any help. I can do it by myself.* No you can't; you've been doing that same problem for fifteen minutes. *Have not!* Have so. And you don't even know fractions, either. You're dumb. *I'm not dumb.* Yes, you are. Tedd-y's a dumb-bell, Tedd-y's a dumb-bell. *You big meanie; you just think you're so smart.* Tedd-y's a dumb-bell, and a cry-baby. *Stop it, you meanie.* Tedd-y's a cry-baby. Cry-baby.

Oh–there goes my glass. . . . There's Roo; she's running away from the sound–that's it! That's the funny thing. I remember now: it was the mandrills at the zoo, and how they would run back and forth inside their cages, and when they ran away from me I saw they had no fur on their behinds. It was so funny! As if they had sat in one place too long and the fur had all worn off. I still have to laugh.

Roo, you should have seen them. You would have laughed; it was exactly like when you ran away just now, but *no fur.* Honest to God, Roo. I just have to laugh.

Roo, Roo! Now she's barking. Roo! What's the matter with her? She's making a horrible sound. I can see her teeth. Louise! I can't find Louise. Roo! Roo! It's me; it's your daddy–oh, she won't stop. Help! Louise! *Get away from her! Get away! She's hurt.* What happened to her, Teddy? *It was that big German shepherd on the corner; he got out.* Is she going to be okay? *I can't tell yet. Take her collar off; she's bleeding.* Jane started to cry. *Why did you let her out? She always goes over to that house. That dog is vicious.* Louise! Help! Help!

She is behind me; I can feel her arms, but Roo is still coming at me. Louise, save me! Her arms are around me. I'm just going to hold on and close my eyes. As long as I can feel Louise there, I'm safe. As long as I can touch her hands.□

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